Tinnitus experience in deaf and severe-profound hearing-impaired adults in the United Kingdom and Saudi Arabia.

Lama Alzahrani, M.D.

Thesis submitted to the University of Nottingham for the degree of Doctor of Philosophy.

ABSTRACT

Tinnitus is an auditory condition characterised by the perception of sound without any external source. For some individuals, it becomes a chronic condition associated with functional and emotional difficulties, often referred to as tinnitus disorder. While considerable research has explored tinnitus in the general population, there is a notable lack of evidence concerning how tinnitus is experienced and managed by those who are Deaf or have severe-to-profound hearing loss. This PhD study aimed to address this gap by exploring the lived experience of tinnitus in this population and identifying suitable tinnitus questionnaires for assessment and management.

A scoping review was conducted to examine existing literature on tinnitus in people who are Deaf and with severe-to-profound hearing loss. The review revealed that cochlear implants are the most commonly used treatment for this group, typically when deafness is the primary indication and tinnitus is assessed as a secondary outcome. It also highlighted a significant lack of research into the lived experiences of tinnitus in this population, underscoring the need for further investigation.

Following the review, the study proceeded in two phases. Phase One focused on exploring the lived experience of tinnitus among adults with severe-to-profound hearing loss through a mixed method approach. Participants were recruited from the United Kingdom and Saudi Arabia. The quantitative component employed the Tinnitus Handicap Inventory (THI) to assess tinnitus severity and the Depression, Anxiety, and Stress Scale (DASS) to measure associated psychological comorbidities. Semi-structured interviews provided deeper insights into personal experiences. Notably, most Saudi participants were congenitally deaf or deafened in early childhood and used Saudi Arabian Sign Language, while the UK sample included both congenitally and late-deafened individuals.

Results indicated variability in tinnitus severity, with different levels of perceived handicap. Both groups reported high levels of anxiety, with depression and stress reported to a lesser extent. Framework analysis of the qualitative data identified three key themes: the characteristics of tinnitus, its impact on daily life, and the adequacy of healthcare services. These findings highlight the need for tailored tinnitus management strategies for this population.

Phase two aimed to identify commonly reported tinnitus-related problems in the given population and map them onto existing tinnitus questionnaires to evaluate their content validity and relevance. A qualitative content analysis of the interview data was conducted, and the extracted problems were matched against the content of several tinnitus questionnaires. The Tinnitus Questionnaire (TQ), Tinnitus Handicap Questionnaire (THQ), Tinnitus Severity Scale (TSS), and Tinnitus Functional Index (TFI) were found to be the most comprehensive and potentially suitable tools for assessing tinnitus in adults with severe-to-profound hearing loss or deafness.

Overall, this study emphasises the importance of incorporating the perspectives of deaf and severely hearing-impaired individuals into tinnitus research and the need for validated assessment tools tailored to their unique needs.

ACKNOWLEDGMENT

I am immensely grateful to the wonderful individuals I had the pleasure of encountering on this remarkable journey. I would like to take this opportunity to express my heartfelt appreciation to my exceptional supervisory team for their invaluable guidance and unwavering support throughout my PhD journey. Without them, my thesis would not have been successfully completed. I consider myself fortunate to have had them as mentors, especially during the challenging times of the Covid pandemic, where their empathy and support were truly overwhelming.

I would like to extend my sincere appreciation to Derek Hoare for his constant availability and willingness to provide guidance whenever I encountered any challenges.

To Magdalena Sereda for her consistent approach and meticulous attention to detail, from which I have learned valuable lessons.

To Rebecca Dewey for her valuable assistance, particularly in participant recruitment.

To my extraordinary parents, both my mother and father, who have continuously offered me boundless opportunities and motivated me to pursue excellence, even in challenging circumstances.

To my husband, Saif, and my wonderful daughter, Sarah, Sama and Heba who bring so much joy and light into my life.

I express my gratitude to the participants from both the United Kingdom and Saudi Arabia, who played a central role in my thesis.

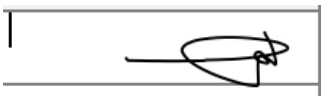
In memory of my late brother-in-law Ahmed, who regrettably passed away in April 2020, I would like to pay my respects. Ahmed was renowned for his extraordinary empathy and considerate demeanour, and his memory will forever be cherished.

PUBLICATION

Alzahrani, L., Sereda, M., Chamouton, C. S., Haider, H., Dewey, R. & Hoare, D. (2022) Experience of tinnitus in adults who have severe-profound hearing loss: A scoping review. Front. Neurol. 13:1004059 https://doi.org/10.3389/fneur.2022.1004059

DECLARTION

I hereby affirm that this thesis is entirely my own work, except for instances where I have cited references. I have not previously submitted any portion of this thesis for any other academic degree or qualification.



12 May 2025

Lama Alzahrani Date

COVID IMPACT

My PhD program began in February 2020, right as the COVID-19 pandemic was starting. This has had a significant impact on my journey. Firstly, the pandemic disrupted my research plans and required me, like everyone else, to adapt to new circumstances. Additionally, the transition to remote work and online learning presented challenges, especially with having two children at home. Balancing my work and being present for my children was an added burden. The uncertainty and stress of the global crisis made it difficult to stay focused and motivated. The lack of social interactions and support systems made the PhD journey feel isolating and lonely. Although restrictions were lifted in March 2021, there has always been a persistent sense of maintaining distance. Even upon returning to work, the rule of having a minimum number of people in the offices posed challenges.

Luckily, I was privileged to have exceptional supervision throughout this period. Despite being physically apart, I felt a strong sense of belonging within a closely-knit community. The team consistently provided support, shared knowledge, and created a nurturing atmosphere for one another.

Overall, COVID-19 has greatly disrupted my PhD experience, imposed limitations and increased stress.

Contents

ABSTRACT 2
ACKNOWLEDGMENT 4
PUBLICATION 6
DECLARTION 7
COVID IMPACT 8
LIST OF TABLES 14
LIST OF FIGURES 16
LIST OF ABBERVATIONS 18
THESIS OVERVIEW 21
Chapter 1 Hearing, deafness and tinnitus 23
1.1. Basic anatomy and physiology of the auditory system 23
1.1. The Peripheral Auditory System 24
1.2. The Central Auditory System 30
1.2. Hearing loss and deafness 34
1.2.1. Definitions, categories, and prevalence 34
1.2.2. Hearing loss risk factors and pathophysiology 39
1.2.3. The impact of hearing loss 41
1.2.4. Clinical management of hearing loss and deafness 46
1.3. Tinnitus 52
1.3.1. Definitions, categories, and prevalence 52
1.3.2. Tinnitus risk factors, pathophysiology, and models 57
a) Psychological habituation model 61
b) Neurophysiological model 62
c) Fear-avoidance model 63
d) Cognitive Behavioral Model 64
e) Neuro-mechanical framework of tinnitus 65
1.3.3. Tinnitus impact 65
1.3.4. Tinnitus management 67
1.3. The lived experience of tinnitus 72
1.4. Gaps in the literature on tinnitus in adults who are D/deaf or have severe-to profound hearing loss 75
1.5. Study aims and objectives 77
Chapter 2 A Scoping review to analyse what exists in the literature regarding tinnitus management in deaf and severe-profound hearing-impaired adults. 79
2.1 Introduction 79
2.1.1 Aim and objectives 79
2.2 Methods 80

2.2.1 Eligibility criteria 80
2.2.2 Information sources 81
2.2.3 Search strategy 81
2.2.4 Selection of source of evidence 82
2.2.5 Data charting process 82
2.2.6 Data items 82
2.3 Results 83
2.3.1 Study demographic 84
2.3.2 Study Population 94
2.3.3 Theme 1: Impact of tinnitus in the D/deaf and adults with severe-to-profound hearing loss 94
2.3.4 Theme 2: Primary treatment of tinnitus in D/deaf adults 105
2.3.5 Theme 3: Cochlear implant studies where tinnitus was a secondary outcome 106
2.3.6. Recommendations for future research in the included studies 109
2.4 Discussion 110
2.4.1 Tinnitus experience/impact 110
2.4.2 Primary treatment of tinnitus in deaf adults 111
2.4.3 Cochlear implant studies where tinnitus was a secondary outcome 112
2.4.4 Research recommendations 114
Chapter 3 Methodology and general methods 116
3.1 Introduction 116
3.2 Ethical consideration 117
3.2.1 Confidentiality and anonymity 117
3.2.2 Data storage 117
3.2.3 Withdrawal 117
3.3 Description of the study 118
3.4 Methods 119
3.4.1 Questionnaire measures of tinnitus impact and associated comorbidities 120
I. Tinnitus Handicap Inventory English version 120
II. Tinnitus Handicap Inventory Arabic version 123
III. Depression, Anxiety and Stress Scale English version 125
IV. Depression, Anxiety and Stress Scale Arabic version 127
V. Rationale for using the Tinnitus Handicap Inventory and Depression, Anxiety and Stress Scale. 127
VI. Quantitative analysis 128
3.4.2 Semi-structured interviews: Tinnitus experience 128
I. Participant criteria 129
II. Sampling and recruitment 129
III. Study settings 131

IV. Data collection 131
V. Qualitative data analysis 132
Step 1: Data familiarisation 133
Step 2: Identifying a thematic framework 133
Step 3: Indexing 134
Step 4: Charting 134
Step 5: Mapping and interpretation 134
VI. Reflexivity and personal motivation 134
Chapter 4 The lived experience of tinnitus in deaf and severely-to-profoundly hearing-impaired Saudi Arabian adults. 136
4.1 Introduction 136
4.1.1 Aim 138
4.1.2 Objectives 138
4.2 Methods 138
4.2.1 Quantitative data 138
4.2.2 Qualitative data 139
4.3 Results 139
4.3.1 Quantitative findings 139
4.3.2 Qualitative findings 143
I. Characteristics of tinnitus 143
II. Tinnitus impact 145
III. Healthcare provision to treat tinnitus 149
4.3.3 Mixed methods findings 152
4.4 Discussion 152
4.4.1 Tinnitus severity and impact 152
4.4.2 Tinnitus-associated comorbidities 153
4.4.3 Interviews key findings 156
4.5 Conclusion 158
Chapter 5 The lived experience of tinnitus in deaf and severely-to-profoundly hearing-impaired adults in the United Kingdom. 161
5.1 Introduction 161
5.1.1 Aim 162
5.1.2 Objectives 162
5.2 Methods 162
5.2.1 Quantitative data 162
5.2.2 Qualitative data 163
5.3 Results 163
5.3.1 Quantitative findings 163

5.3.2 Qualitative finding 167
5.3.3 Mixed methods finding 185
5.4 Discussion 186
5.4.1. Tinnitus severity and impact 186
5.4.2 Tinnitus-associated comorbidities 187
5.4.3 Interviews key findings 188
5.5 Conclusion 193
Chapter 6: Mapping the tinnitus-related problems of deaf adults to tinnitus questionnaires 195
6.1 Introduction 195
6.1.1 Aim 199
6.1.2 Objectives 199
6.2 Method 200
6.2.1 Stage 1: Identification of Commonly Reported Problems Across Study Samples Using Qualitative Content Analysis 200
6.2.2 Stage 2: Content Validity of the Available Tinnitus Questionnaires to the Reported Problems Extracted from the Interviews 205
6.3 Results 213
6.3.1 Stage 1. Frequently reported problems 213
6.3.2 Stage 2: Content Validity 221
6.4 Discussion 227
6.5 Conclusion 231
Chapter 7: General discussion 233
7.1 Study findings 234
7.2 Study implication 241
7.3 Future recommendation 242
7.4 Conclusion 243
Appendices 245
Appendix 1 Study ethical approval 245
Appendix 2 Participant consent form 246
Appendix 3 Invitation letters, Arabic and English 247
Appendix 4 Tinnitus Handicap Inventory, English version 249
Appendix 5 Tinnitus Handicap Inventory, Arabic version 252
Appendix 6 Depression, Anxiety, Stress Scale, English version 253
Appendix 7 Depression, Anxiety, Stress Scale, Arabic version 255
Appendix 8 Demographic sheet and interview guide 256
Appendix 9 The thematic framework 260
Appendix 10 problems identified by stakeholders among study participants 263
Appendix 11 An example of questionnaire (Tinnitus Questionnaire) items coding among stakeholders and final decision 264

References: 266

LIST OF TABLES

Table 1.1 Global burden of disease hearing loss classification (Haile et al., 2021)…….....37

Table 1.2 Main difference between congenital and acquired hearing loss (Lieu et al., 2020)…….38

Table 1.3 Risk factors for hearing loss according to age (WHO, 2023)……..40

Table 1.4 Hearing loss/ deafness impact at three main levels: the individual, family/communicating partner, and economic impact (adapted from World report on hearing, WHO, 2021)…….42

Table 2.1 Inclusion and exclusion criteria……82

Table 2.2 An example of search strategy used for MEDLINE via OVID SP……..83

Table 2.3 The characteristic of included studies……..89

Table 2.4 Intervention used to assess and treat tinnitus……...……97

Table 3.1 Tinnitus Handicap Inventory (THI) subscales and what they cover……..121

Table 3.2 Tinnitus Handicap Inventory Scores and grades……122

Table 3.3 Depression, Anxiety and Stress Scale total scores for each subscale and grade……...127

Table 4.1 Demographic summary of included SA participants…….141

Table 5.1 Demographic summary of included UK participants……163

Table 6.1 Tinnitus-related problems based on World Health Organization Classification. Adapted from Hall et al. (2018)…….200

Table 6.2 Characteristic of the included tinnitus questionnaires……....204

Table 6.3 Reported problems among the study samples……....211

Table 6.4 Tinnitus questionnaires which comprehensively addressed the problems identified by the UK sample……...220

Table 6.5 Tinnitus questionnaires which comprehensively addressed the problems identified by the SA sample ……..….221

LIST OF FIGURES

Figure 1.1 The Auditory System (Pelle, 2023)……25

Figure 1.2 Anatomy of the Ear (Blausen.com staff, 2014)……..26

Figure 1.3 Organ of Corti, the hearing receptor present in the inner ear (adapted from Service Medical Art, 2013)……...27

Figure 1.4 Mechanoelectrical transduction in hair cells……..….29

Figure 1.5 Human auditory cortex localisation on the superior temporal gyrus (STG) of the temporal lobe……....33

Figure 1.6 Hearing loss classified by anatomical site……..….35

Figure 1.7 Hearing aid components(battery). …….48

Figure 1.8 Cochlear implant components.……..….49

Figure 1.9 Tinnitus classification based on onset, aetiology, origin, and psychosocial impact. ……...…..53

Figure 2.1 Flowchart showing the process of extracting, screening and analysing data…….84

Figure 2.2 Distribution of included studies by year…….85

Figure 2.3 Distribution of included studies by country of origin ……86

Figure 3.1 Concurrent triangulation mixed-methods design (adapted from Creswell, 2003)……...118

Figure 3.2 Timeframe used in data collection from both study samples……...…119

Figure 6.1 Flowchart outlining the approach for identifying tinnitus questionnaires included for assessment of content validity with respect to reported problems……...203

Figure 6.2 Reported problems in physical domains in a United Kingdom (UK, in blue) and Saudi Arabia (SA, in green) sample. ……....213

Figure 6.3 Reported problems in psychological domains-Functional difficulties due to tinnitus in a United Kingdom (UK, in blue) and Saudi Arabia (SA, in green) sample…..…214

Figure 6.4 Reported problems in psychological domains- Tinnitus related distress in a United Kingdom (UK, in blue) and Saudi Arabia (SA, in green) sample……..…....215

Figure 6.5 Reported problems in the negative attributes of tinnitus sound in a United Kingdom (UK, in blue) and Saudi Arabia (SA, in green) sample……..…....216

Figure 6.6 Reported problems in the Independence domain in a United Kingdom (UK, in blue) and Saudi Arabia (SA, in green) sample. …….....217

Figure 6.7 Most reported problems in the study samples (UK and SA) across three domains: physical, level of independence, and negative attributes of tinnitus sound……...218

Figure 6.8 Coverage of reported problems by twenty-three questionnaires reported by UK participants…….....222

Figure 6.9 Coverage of reported problems by twenty-three questionnaires reported by SA participants…….223

LIST OF ABBERVATIONS

A1 Primary Auditory Cortex

A2 Secondary Auditory Cortex

ASHA American Speech-Language-Hearing Association

AVCN Anterior Ventral Cochlear Nucleus

BSA British Society of Audiology

BDI Beck's Depression Inventory

CBT Cognitive Behavioural Therapy

CHL Conductive Hearing Loss

CI Cochlear Implant

CN Cochlear nucleus

CVC Consonant-Vowel-Consonant

COVID-19 Coronavirus Disease 2019

CORE Clinical Outcomes in Routine Evaluation

CTAQ Chronic Tinnitus Acceptance Questionnaire

DASS Depression, Anxiety, Stress Scale

DT discomfort from tinnitus

4DSQ Four-Dimensional Symptom Questionnaire

tDCS transcranial Direct Current Stimulation

EAC External Auditory Canal

EPS Electrical Promontory Stimulation

FTQ Fear of Tinnitus Questionnaire

GJB2 and GJB6 Gap Junction Beta-2 protein & Gap Junction Beta-6 protein.

GBD Global Burden of Disease

HRQoL Health Related Quality of Life

IC Inferior Colliculus

IHC Inner Hair Cell

IPQ-M Modified Illness Perception Questionnaire

ITI International Tinnitus Inventory

OHC Outer Hair Cell

VCN Ventral Cochlear Nucleus

LSO Lateral Superior Olivary Nucleus

MESH Medical Subject Headings

MGB Medial Geniculate Body

MGV Ventral division of Medial Geniculate Body

MGM Medial division of Medial Geniculate Body

MGD Dorsal division of Medial Geniculate Body

Mini TQ12 Mini Tinnitus Questionnaire 12

MML Minimum Masking Level

MNTB Medial Nucleus of the Trapezoid Body

MSO Medial Superior Olivary Nucleus

MSPQ Modified Somatic Perception Questionnaire

MOC Medial Olivocochlear System

NICE National Institute for Health and Care Excellence

PVCN Posterior Ventral Cochlear Nucleus

PROM Patient-Reported Outcome Measure

SNHL Sensory Neural Hearing Loss

SOC Superior Olivary Complex

STSS Subjective Tinnitus Severity Scale

SETMQ Self-Efficacy for Tinnitus Management Questionnaire

STS Skarzynski Tinnitus Scale

STL Subjective Tinnitus Loudness

SQ Perceived Stress Questionnaire

STAI : State Trait Anxiety Inventory

TAQ : Tinnitus Acceptance Questionnaire

TCQ Tinnitus Cognition Questionnaire

TCS Tinnitus Catastrophizing Scale

TCSQ Tinnitus Coping Style Questionnaire

TDI Tinnitus disability Index

TFAS Tinnitus Fear Avoidance Scale

TFI Tinnitus Functional Index

THI Tinnitus Handicap Inventory

THQ Tinnitus Handicap Questionnaire

THS Tinnitus and Hearing Survey

TIQ Tinnitus Impact Questionnaire

TMI Tinnitus Magnitude Index

rTMS repetitive Transcranial Magnetic Stimulation

TPFQ Tinnitus Primary Function Questionnaire

TQ Tinnitus Questionnaire

TRQ Tinnitus Reaction Questionnaire

TRT Tinnitus retraining therapy

TSI Tinnitus Severity Index

TSS Tinnitus Severity Scale

TVAQ Tinnitus Vigilance and Awareness Questionnaire

VAS Visual Analogue Scale

WHO World Health Organization

THESIS OVERVIEW

This thesis explores tinnitus in Deaf and severely-to-profoundly hearing-impaired adults, with a focus on two study samples, from Saudi Arabia and the United Kingdom. The objective was to address the gaps in understanding, assessment, and management strategies for tinnitus in this population, and to identify suitable tools for evaluating tinnitus in the given populations.

Chapter 1 addresses the normal anatomy of the ear and then defines two of the main symptoms which are deafness and tinnitus. It defines deafness, categorises different levels of hearing loss, and discusses the prevalence, risk factors, and the general pathophysiology of hearing loss. Additionally, it reviews the impact of hearing loss and the assessment and management of severe-to-profound hearing impairment in adults, including the latest guidelines. Finally, it delves into the risk factors, pathophysiology, and models of tinnitus, as well as the latest strategies for its assessment and management. The chapter concludes by exploring the lived experiences of adults with tinnitus and identifying gaps in research related to tinnitus in individuals who are Deaf or have severe-to-profound hearing loss.

Chapter 2 presents a scoping review that characterises the current literature on the assessment of tinnitus in Deaf or severe-profound hearing-impaired adults. The review highlights a significant gap in dedicated research for this population, with most existing studies primarily focusing on cochlear implant provision for severe-to-profound hearing loss and treating tinnitus assessment as a secondary outcome. There is a notable lack of empirical studies exploring the nature of tinnitus in individuals with little to-no-residual hearing.

Chapter 3 discusses the methodology employed in this thesis, which adopts a pragmatic mixed-methods approach. This methodology is flexible and adaptable, accommodating the unique nature of the project and its participants.

Chapters 4 and 5 focus on the lived experiences of tinnitus in Deaf and severely-to-profoundly hearing-impaired adults from Saudi Arabia and the UK. Tinnitus severity was assessed using the Tinnitus Handicap Inventory (Arabic and English versions), and associated comorbidities were assessed using the Depression, Anxiety, Stress Scale in the same two languages. Semi-structured interviews were conducted, and the data were analysed using a Framework approach. This analysis resulted in significant themes and subthemes, supported by relevant quotes, shedding light on the tinnitus experience in these populations.

Chapter 6 aims to identify the most suitable tinnitus questionnaire for this population. This process involved a content analysis to identify commonly reported problem domains in the study samples, and mapping these domains to the available tinnitus questionnaires.

Finally, Chapter 7 presents a summary of the main findings, discusses the strengths and limitations of the study, and concludes with recommendations for future research in this area.

Through this research, the thesis aims to contribute to the understanding of tinnitus in deaf and severely-to-profoundly hearing-impaired adults and inform more effective assessment and management strategies for this underserved population.

Chapter 1 Hearing, deafness and tinnitus

1.1. Basic anatomy and physiology of the auditory system

The auditory system plays a vital role in our ability to sense and engage with our surroundings. It comprises the peripheral auditory system, which encompasses the ear's functions in receiving and conveying sound, and the central auditory system that spans from the brainstem to the auditory cortex, tasked with processing and interpreting sounds. Figure 1.1 illustrates the auditory system.

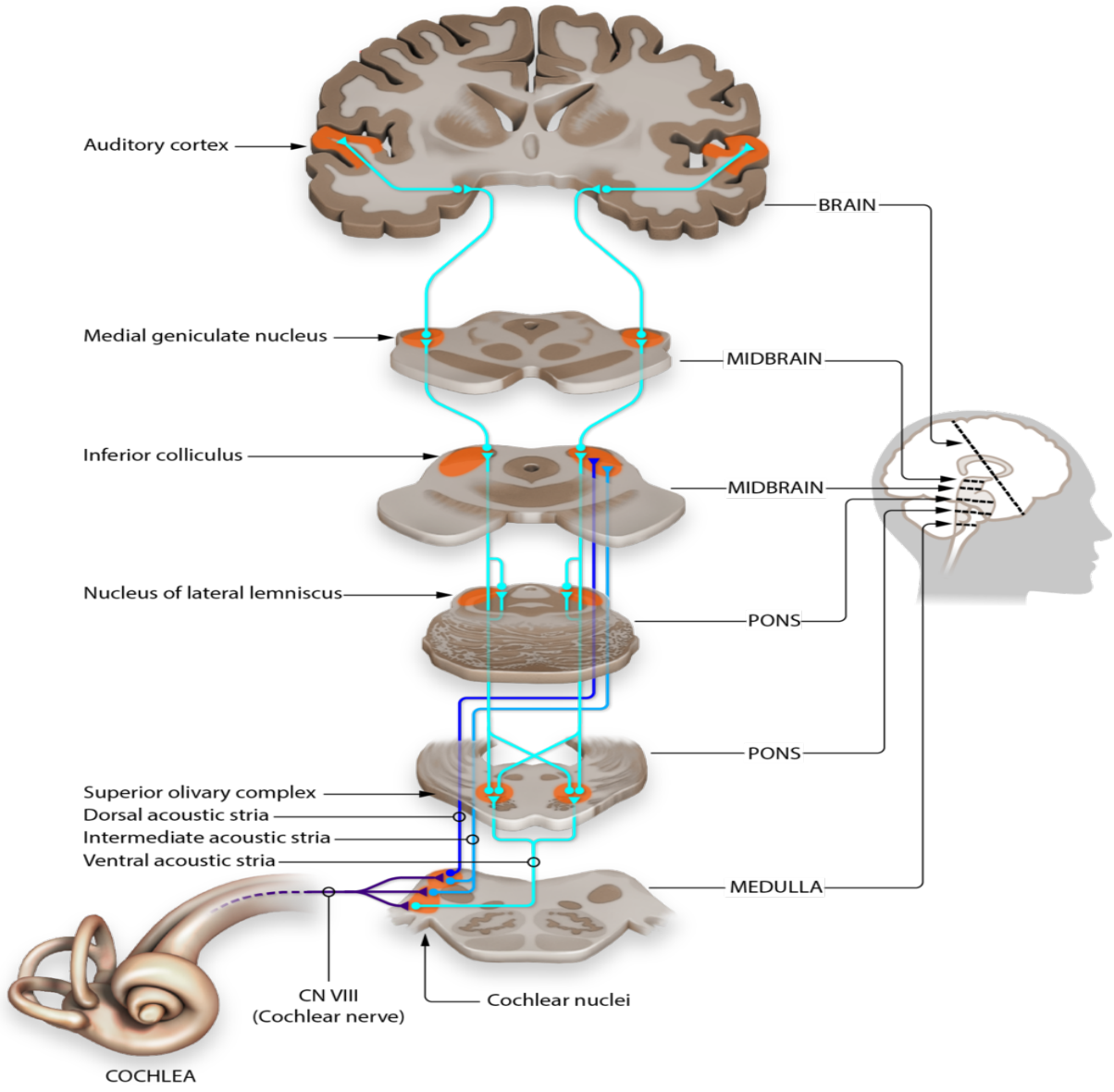


Figure 1.1 The Auditory System. The peripheral auditory system is represented by the cochlea in the inner ear while the central auditory system is represented by the cochlear nuclei, superior olivary complex, lateral lemniscus, inferior colliculus, medial geniculate body and finally the auditory cortex in the temporal lobe (Pelle, 2023).

1.1. The Peripheral Auditory System

The ear represents the peripheral auditory system and is divided into three main parts that are anatomically and functionally different (Figure 1.2).

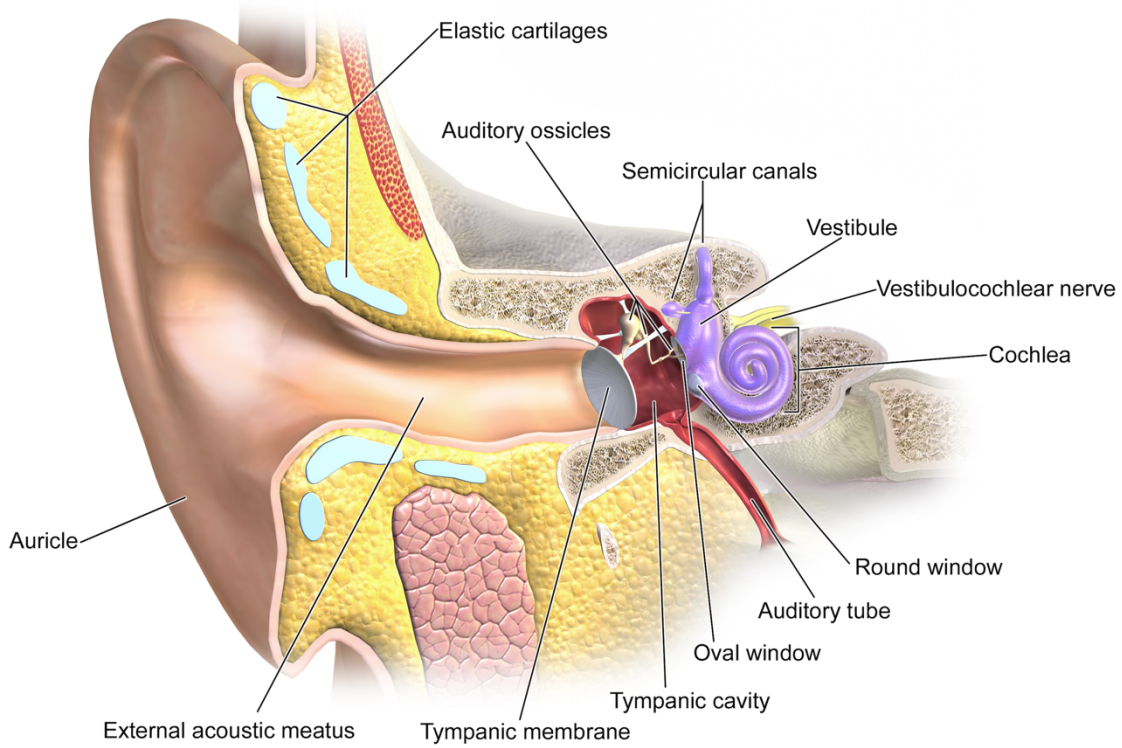


Figure 1.2 Anatomy of the Ear (Blausen.com staff, 2014).

a) The external ear is composed of the auricle, a cartilaginous curved structure that collects sound vibrations and transmits them to the external auditory canal (EAC) (Sheikh et al., 2022). The EAC, approximately 2.5 cm long, contains hair and sebaceous and ceruminous glands.

b) The middle ear is an air-filled cavity connected to the nasopharynx via the Eustachian tube (He et al., 2022; Sheikh et al., 2022). It contains three small bones—the malleus, incus, and stapes—responsible for transmitting sound from the tympanic membrane to the inner ear.

c) The inner ear is located between the middle ear and the internal auditory meatus within the petrous portion of the temporal bone (Bohne & Harding, 2008). It consists of the bony labyrinth, which includes the cochlea, vestibules, and three semi-circular

canals, and the membranous labyrinth, comprising a series of interconnected sacs and ducts suspended within the bony labyrinth. The cochlea is a spiral structure, typically around 30-35 mm in length, with approximately 2.5 turns (Pickles, 2015). It is a fluid-filled cavity divided into three main sections: the scala vestibuli, scala media, and scala tympani (Sheikh et al., 2022.). The scala vestibuli and scala tympani are both filled with perilymph, which is similar to extracellular fluid and high in sodium concentration but low in calcium and potassium. The scala media, on the other hand, is filled with endolymph, which is high in potassium and low in sodium and calcium. The scala media is separated from the scala tympani by the basilar membrane and from the scala vestibuli by Reissner's membrane.

The Organ of Corti, the cochlea's primary hearing receptor, rests on the basilar membrane within the scala media (Figure 1.3). It is the crucial unit for sound perception, as it converts the mechanical energy of sound waves into nerve impulses. The Organ of Corti is composed of the following structures:

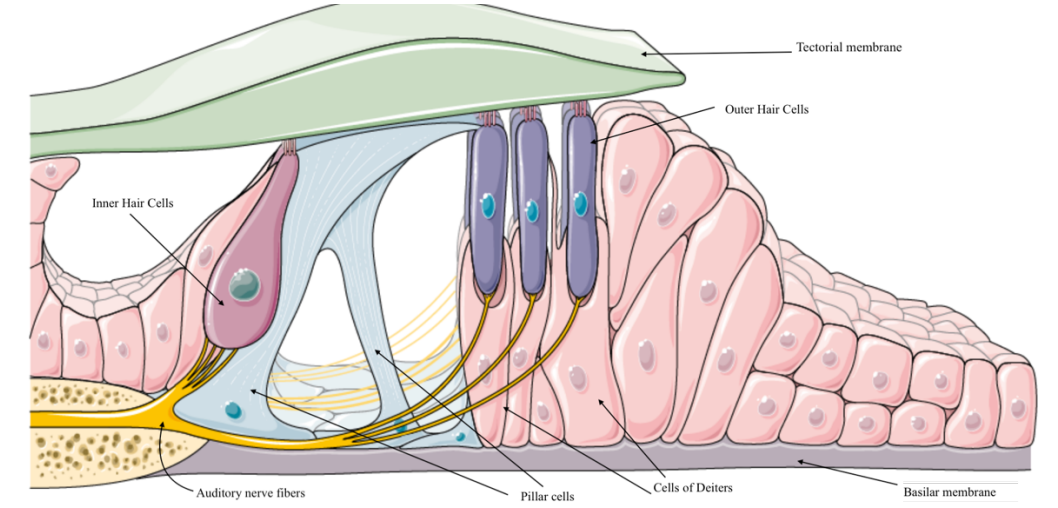


Figure 1.3 Organ of Corti, the hearing receptor present in the inner ear (adapted from Service Medical Art, 2013)

a) Hair cells: The Organ of Corti contains two types of mechanosensory hair cells: inner hair cells (IHCs) and outer hair cells (OHCs). These cells differ significantly in morphology and function. The Organ of Corti typically includes one row of IHCs (approximately 4,000) and three rows of OHCs (about 20,000) (Bohne & Harding, 2008; Sheikh et al., 2022 Zheng & Holt, 2021). IHCs are flask-shaped with a centrally located nucleus and are generally immobile. They are responsible for transmitting auditory information to the higher auditory centres. In contrast, OHCs are long and cylindrical, with their nucleus located near the base. They are mobile due to the presence of the Prestin protein, which allows them to play a crucial role in sound amplification and frequency tuning (Fettiplace, 2023; He et al., 2022). Both types of hair cells have specialised epithelial structures called stereocilia on their apical surface. However, the arrangement and connection of these stereocilia differ between IHCs and OHCs. The stereocilia of OHCs are firmly embedded in the tectorial membrane, while those of IHCs make a more tenuous connection (Pelaseyed & Bretscher, 2018). The stereocilia are arranged in a stair-like pattern from shorter to taller, and each stereocilium is connected to its neighbour via tip links (Fettiplace & Kim, 2014; Zheng & Holt, 2021)(Figure 1.4).

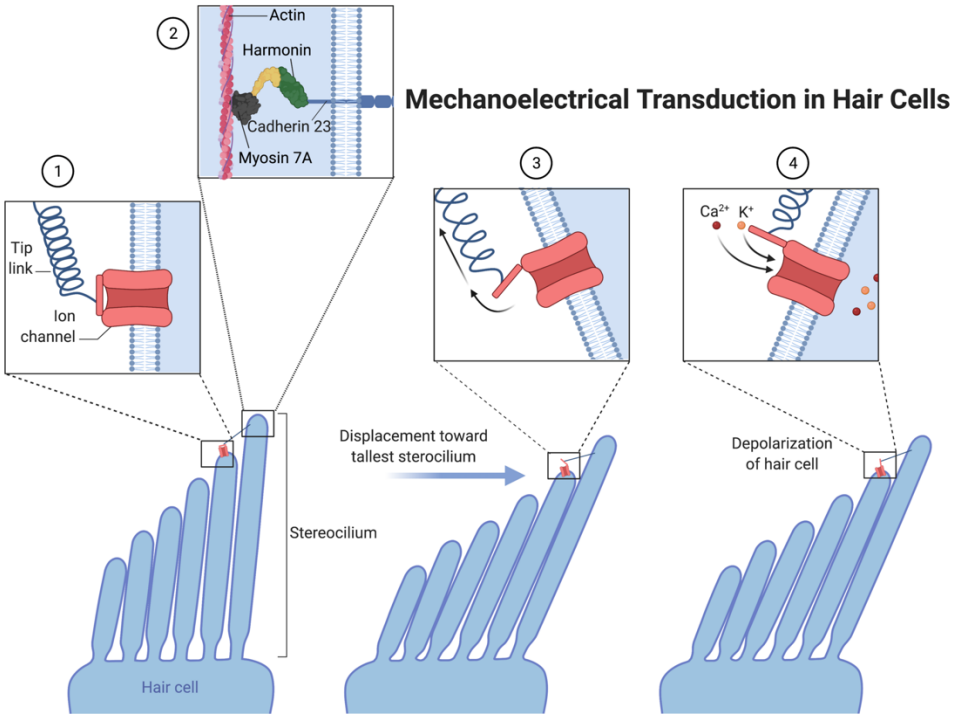


Figure 1.4 Mechanoelectrical transduction in hair cells. Tip links connect stereocilia at the apical hair bundle. Deflection of the bundle toward the tallest stereocilia increases tension in tip links, opening mechanoelectrical transduction (MET) channels. This allows influx of cations. (Adapted from Cochleae, *Mechanoelectrical transduction in hair cells*, Wikimedia Commons, CC BY-SA 4.0)

b) Basilar membrane: This serves as a structural foundation supporting the overlying hair cells. It is thick and narrow at the base of the cochlea and thin and sensitive at the apex (Mao et al., 2020; Warren & Fridberger, 2015). The basilar membrane follows a tonotopic organisation, which is the spatial representation of sound frequencies along its length. This organisation allows sound frequencies to be maintained and transmitted to higher auditory centres (Fettiplace, 2023). This feature is present in all vertebrates that perceive airborne sounds and plays a crucial role in decomposing complex sounds into their component frequencies (Mann & Kelley, 2011).

c) Tectorial membrane: This plays a significant role in the active amplification of cochlear responses to acoustic frequencies (Mann & Kelley, 2011). It is in direct contact with the OHCs and influences the deflection of IHC bundles through fluid movement (Mao et al., 2020). This membrane enables a wide dynamic range for sound perception. It is composed of water, glycosaminoglycans, and both collagenous and non-collagenous proteins, which are essential for its function (Sellon et al., 2019). The tallest stereocilia of the OHCs are attached to the tectorial membrane, whereas those of the IHCs are not (Verpy et al., 2011). Stereocilia are actin-based protrusions found on both auditory and vestibular sensory cells, including those in OHCs and around the tectorial membrane. They are crucial for hearing and balance, as they convert physical forces from sound, head movement, or gravity into electrical signals through a process known as mechanoelectrical transduction. This process is vital for OHCs to perform sound amplification.

d) Supporting cells: The organ of Corti contains several types of supporting cells which play a crucial role in maintaining the structural integrity of hair cells and ensuring proper auditory function (Giese et al., 2024; Mao et al., 2020; Sheikh et al., 2022). These supporting cells include Hensen's cells, Deiters' cells (also known as phalangeal cells), Claudius's cells, Boettcher's cells, and the cells of the outer and inner pillar of Corti (forming the Triangle of Corti). In lower vertebrates, Deiters' cells have the ability to differentiate into hair cells if the original hair cells are lost, a capacity does not present in humans (Liu et al., 2018). This regenerative capability highlights the diverse roles supporting cells can play in different species.

e) Auditory nerve: The auditory nerve is formed by projections from the spiral ganglion and, together with the vestibular branch, constitutes the eighth cranial nerve (Pickles, 2015). This nerve plays a crucial role in transmitting auditory information from the cochlea to the central auditory system. Specifically, it innervates the cochlear nuclei located in the brainstem, which serve as the initial processing stage for auditory signals.

1.2. The Central Auditory System

The central auditory system consists of multiple subcortical relay neurons extending from the brainstem to the auditory cortex (Figure 1.1). As sound signals are transmitted by the auditory nerve, they pass through several stations along the central auditory pathway. Each of these relays possesses distinct morphological characteristics and contributes uniquely to sound processing. The auditory pathway involves several key structures, including the cochlear nuclei, superior olivary complex, nuclei of the lateral lemniscus, inferior colliculus, and medial geniculate nucleus of the thalamus.

a) Cochlear nuclei: The cochlear nuclei are two primary auditory nuclei located in the brainstem, organized into the ventral cochlear nucleus (VCN) and the dorsal cochlear nucleus (DCN) (Pickles, 2015). The VCN is situated anteriorly and is further divided into the anterior ventral cochlear nucleus (AVCN) and the posterior ventral cochlear nucleus (PVCN). Auditory fibres traverse these nuclei, forming two main pathways: the ventral pathway and the dorsal pathway. The ventral pathway primarily innervates the AVCN, which plays a crucial role in binaural sound localisation. The dorsal pathway innervates the PVCN and the DCN, with a primary function in sound identification and spectral analysis.

b) Superior olivary complex: The superior olivary complex (SOC) is a group of nuclei located in the pons, playing a crucial role in the auditory system (Pickles, 2015). The SOC includes several key nuclei, primarily the medial superior olivary nucleus (MSO) and the lateral superior olivary nucleus (LSO), along with the medial nucleus of the trapezoid body (MNTB). The SOC is an important site for processing sound localisation and binaural hearing. It receives input from both ears, comparing the timing and intensity of sound signals to determine the location of sound sources. Moreover, The SOC also contributes to the olivocochlear system, which includes descending pathways to the inner hair cells. This system is crucial for the maturation of the central auditory pathway, especially during the prehearing critical period in altricial mammals like humans (Bordeynik-Cohen et al., 2023;Di Guilmi et al., 2019). These efferent connections, mediated by the medial olivocochlear (MOC) system, facilitate proper auditory development before the onset of hearing.

c) Inferior colliculus: The inferior colliculus is a crucial structure located in the midbrain, serving as a key component of the auditory pathway (Pickles, 2015). It plays a pivotal role in processing sound information, particularly in sound localisation and the integration of auditory signals from both ears. The IC receives input from the cochlear nuclei (via the auditory nerve) and the superior olivary complex and then sends processed auditory signals to the medial geniculate nucleus of the thalamus, which relays them to the auditory cortex in the brain. The IC also participates in multisensory integration, receiving inputs from somatosensory nuclei and contributing to the distinction between self-generated and environmental sounds.

d) Medial geniculate body: The auditory thalamus, commonly referred to as the medial geniculate body (MGB), is a complex structure composed of the ventral division (MGV), medial division (MGM), and dorsal division (MGD) (Pickles, 2015). The MGB actively participates in various perceptual tasks, including speech comprehension, speaker identification, and the processing of the emotional aspects of auditory signals (Bartlett, 2013).

e) Auditory cortex: The auditory cortex, located on the lateral surface of the temporal lobe, is the final destination for sound information that has been processed and refined by the auditory pathway. This information exits the MGB in the thalamus and travels to the ipsilateral centres in the temporal lobe (Kiernan, 2012) (Figure 1.5).

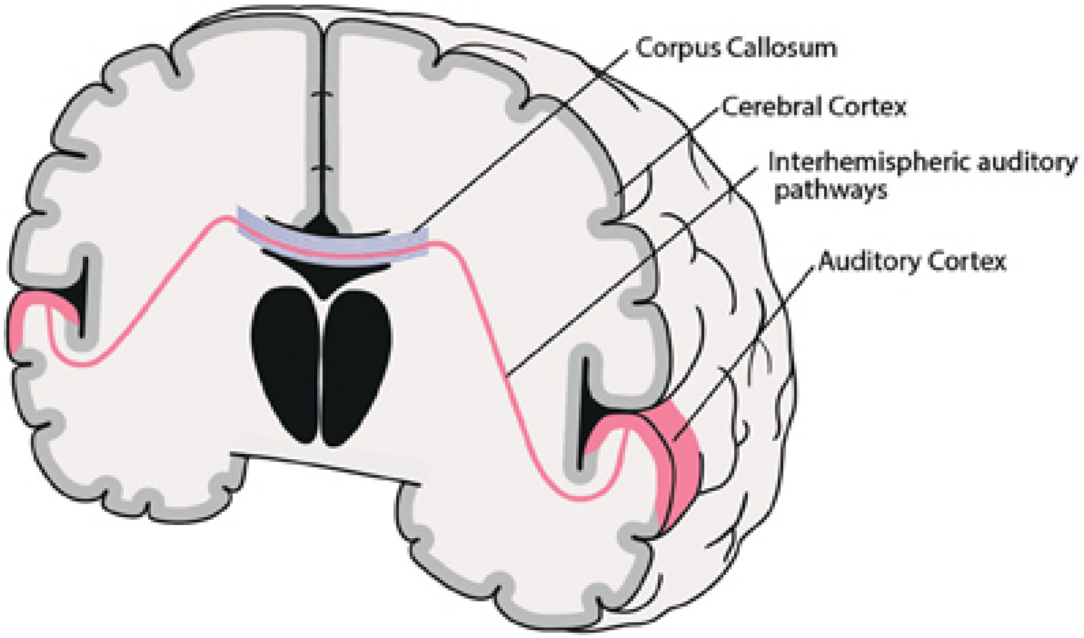


Figure 1.5 Human auditory cortex is primarily located on the superior temporal gyrus (STG) of the temporal lobe, including Heschl's gyrus, which contains the primary auditory areas responsible for processing sound frequencies. This region plays a key role in auditory perception and language comprehension (adapted from Steinmann et al., 2014).

The auditory cortex, located on the superior temporal gyrus and specifically within the transverse temporal gyrus (also known as Heschl's gyrus), is a critical region for sound processing due to its extensive thalamic input (Hackett, 2015; Moerel et al., 2014; Nourski, 2017). It is further subdivided into the core or primary auditory cortex (A1) and the secondary auditory cortex (A2), often referred to as the "belt" area (Hackett, 2015). The human primary auditory cortex is primarily confined to Heschl's gyrus and exhibits a tonotopic organisation, preserving the spatial representation of sound frequencies from the cochlea (da Costa et al., 2011; Hamilton et al., 2021). This organisation allows for the precise processing of sound frequencies, aiding in accurate auditory perception. The secondary auditory cortex occupies a larger area and plays a significant role in sound localisation and the analysis of complex sounds, including specific animal vocalisations and human language.

Located on the temporal lobe, the auditory cortex is adjacent to memory and language centres, such as Wernicke's area, and limbic centres, which are involved in emotional processing (Kiernan, 2012). This proximity facilitates the integration of auditory information with other cognitive functions.

In summary, the auditory system consists of peripheral and central components and is characterised by a tonotopic mapping. The peripheral system includes the external ear, middle ear, and inner ear, where sound is collected, transmitted, and converted into electrical signals by the cochlea. These signals are then transmitted via the auditory nerve to the brainstem, passing through key nuclei such as the cochlear nuclei, superior olivary complex, and inferior colliculus. The signals continue to the medial geniculate body and finally to the auditory cortex in the temporal lobe, where they are processed for sound recognition, identification, and emotional context.

1.2. Hearing loss and deafness

1.2.1. Definitions, categories, and prevalence

According to the World Health Organization (2023) hearing loss is defined as the inability to hear as well as someone with normal hearing, where normal hearing is defined as hearing thresholds of 20 dB or better in both ears. Deafness, on the other hand, refers to a complete loss of hearing in one or both ears, with a profound hearing loss characterised by hearing thresholds of 81 dB or greater across the frequencies 0.5, 1, 2, and 4 kHz (WHO, 2023). Hard of hearing is an umbrella term for various degrees of hearing loss, from mild to severe, usually of post lingual onset (Ham et al., 2021). The terms Deaf with an uppercase D, or deaf with a lowercase d, are used to donate specific groups of people who share similar degrees of hearing loss but differ in the way they appreciate it (Hamill & Stein, 2011). The Deaf culture is often identified as an ethnolinguistic minority that takes pride in their Deaf identity, whereas deaf refers to a lack of hearing in general.

Hearing loss can be classified in several ways, including based on the anatomical site, severity, and onset of the loss (Lieu et al., 2020; Michels et al., 2019; Zahnert, 2011). From an anatomical perspective, hearing loss is typically categorised into conductive, sensorineural, mixed, and central types (Michels et al., 2019; Zahnert, 2011). Figure 1.6 illustrates types of hearing loss.

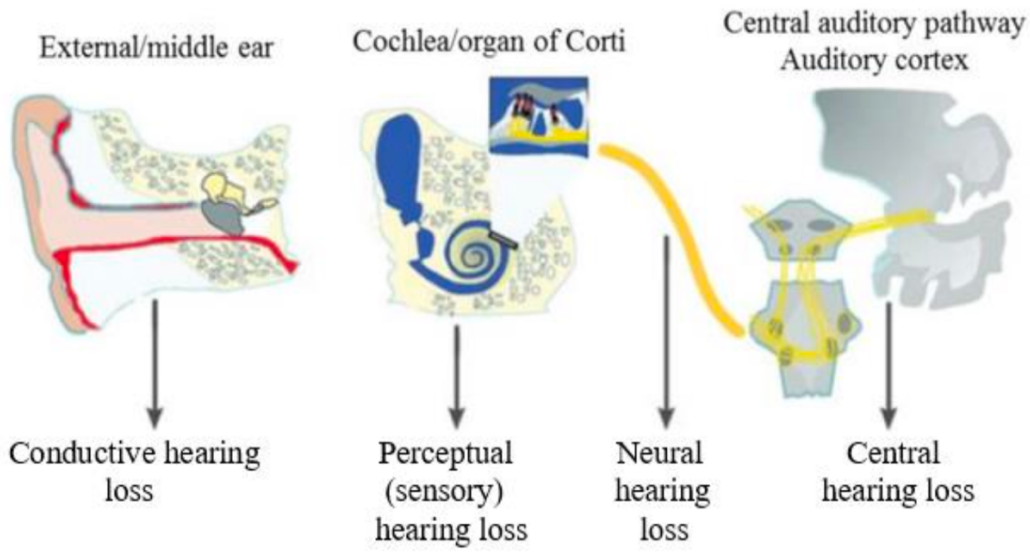


Figure 1.6 Hearing loss classified by anatomical site: conductive hearing loss involves the external or middle ear; sensorineural hearing loss results from damage to the inner ear (cochlea) or auditory nerve; central hearing loss arises from lesions in the central auditory pathways or auditory cortex. Adapted from Zahner et al. (2011).

Conductive hearing loss occurs when sound is not efficiently transmitted through the outer or middle ear, often due to factors such as ear infections, earwax buildup, or damage to the ossicles. Sensorineural hearing loss, which affects the inner ear (the cochlea), can be categorised as sensory or perceptual if the damage is to the cochlea itself or neural if the lesion is in the auditory nerve. This type of hearing loss is often associated with aging, noise exposure, or genetic factors. Mixed hearing loss refers to a combination of both conductive

and sensorineural hearing loss. Central hearing loss occurs when the lesion is located higher in the central auditory pathways. The differentiation between these types of hearing loss is typically based on the clinical history and results from audiological testing (Michels et al., 2019).

In terms of severity, hearing loss is categorised according to a person's average threshold across multiple frequencies as either mild, moderate, severe, or profound based on American Speech-Language-Hearing Association; ASHA (ASHA, 1993). In 2019, a new classification was introduced that includes two health states for each severity category, considering the presence or absence of tinnitus (Haile et al., 2021) (Table 1.2) The significance of acknowledging tinnitus as a symptom frequently linked to hearing loss, which requires attention, is emphasised in this updated classification.

Table 1.1 Global burden of disease hearing loss classification (Haile et al., 2021)

Hearing loss degree	Range	Description
Normal	0-19 dB	Normal hearing
Mild	20-34 dB	Difficulty hearing and understanding in a noisy place.
Mild with ringing	20-34 dB	Difficulty hearing and understanding in a noisy place and has annoying ringing in the ear sometimes.
Moderate	35-49 dB	Difficulty hearing and understanding in a noisy and quite place.
Moderate with ringing	35-49 dB	Difficulty hearing and understanding in a noisy and quite place and has annoying tinnitus in the ears for more than 5 min.
Moderately severe	50-64 dB	No description*
Severe	65-79 dB	Unable to hear and understand another person talking, even in a quiet place, and unable to talk on the phone, difficulties communicating which cause emotional effects (e.g., worry or depression)
Severe with ringing	65-79 dB	Unable to hear and understand another person talking, even in a quiet place, and unable to talk on the phone, difficulties communicating which cause emotional effects (e.g., worry or depression) and ringing in the ear for more than 5 min.
Profound	80-94 dB	Difficulty hearing and understanding in any situation, difficulties in communicating which cause worry, depression, and loneliness.
Profound with ringing	80-94 dB	Difficulty hearing and understanding in any situation, difficulties in communicating which cause worry, depression, and loneliness. Ringing in the ear for more than 5 min.
Complete	95+ dB	Can't hear in any situations including loudest sounds and can't communicate verbally. Difficulties in communicating cause worry, depression, and loneliness.
Complete with ringing	95+ dB	Can't hear in any situations including loudest sounds and can't communicate verbally. Difficulties in communicating cause worry, depression, and loneliness. Ringing in the ear most of the time.

*No description was given to moderately severe hearing loss as it fell between two hearing loss degree categories (moderate severe).

Onset of hearing loss is very important and can be categorised as congenital (present at birth) or acquired (occurring later in life) with each type having a different impact. The main features of congenital and acquired hearing loss are summarised in Table 1.2

Table 1.2 Main difference between congenital and acquired hearing loss (Lieu et al., 2020).

	Congenital	**Acquired**
Onset	Present at birth (pre-lingual)	Develops after birth, at any stage of life.
Causes	Genetic factors, prenatal infections (rubella, CMV), birth complications, prematurity	Age (presbycusis), noise exposure, ototoxic medication, infections, trauma, diseases (e.g., Meniere's disease).
Risk factor	Family history, prenatal infections, prematurity, birth complications	Aging, noise exposure, chronic health conditions (diabetes), ototoxic drugs, trauma.
Speech and communication	Delayed or absent speech development (pre-lingual), reliance on visual communication (sign language, lip-reading). Early intervention (hearing aids, cochlear implants) helps	Preserved speech if post-lingual, but may experience difficulties understanding speech, especially in noise. Progressive decline if untreated.
Role of early intervention	Better outcomes with early intervention (e.g., cochlear implants).	Better outcomes if diagnosed and treated early; adaptation possible but may face progressive challenges.

Prenatal infection such as congenital cytomegalovirus, and genetic hearing loss, are among the common causes of congenital hearing loss (Lieu et al., 2020). Approximately 80% of cases of congenital hearing loss with a hereditary component are non-syndromic, resulting from genes such as GJB2 and GJB6 (Shave et al., 2022). Age related hearing loss (presbycusis), noise induced hearing loss, and ototoxic drug indued hearing loss are the more common causes of acquired hearing loss in adults (Liberman & Kujawa, 2017; Yang et al., 2015). Hearing loss affects approximately 430 million adults and 34 million children worldwide, with the number expected to rise significantly by 2050 (WHO, 2023). The Global Burden of Disease Study (2019) found that 1.57 billion people had hearing loss in 2019, with 430 million experiencing moderate or severe cases (Haile et al., 2021). By 2050, this number is projected to reach 2.45 billion. Hearing loss is the third leading cause of disability, contributing to 43.45 million years lived with disability. Prevalence of hearing loss is higher in males (17.7%) than females (11.9%), and while most cases are mild, disability is more

prevalent in moderate or severe cases. Despite the widespread impact, only 9.7% of individuals with hearing loss use hearing aids, and 32.5% also experience tinnitus. Occupational noise exposure accounts for 11.2% of hearing loss-related disability, highlighting the need for greater intervention and management strategies.

1.2.2. Hearing loss risk factors and pathophysiology

There are several risk factors for hearing loss (WHO, 2023). Common risk factors for hearing loss are summarised according to life stage in Table 1.3

Table 1.3 Risk factors for hearing loss according to age (WHO, 2023)

Age	**Risk factors**
Perinatal period	Genetic factors
	Intrauterine infection
	Hypoxia (birth asphyxia)
	Low birth weight
	Hyperbilirubinemia
Childhood and adolescent	Otitis media
	Meningitis and other infection
Adulthood and older age	Chronic diseases
	Otosclerosis
	Smoking
	Age related sensorineural degeneration.
	Sudden sensorineural hearing loss
Across life span	Loud noise
	Trauma to the ear or head
	Ototoxic medication
	Work related ototoxic chemicals.
	Nutritional deficiencies

In terms of pathophysiology, any insult to any site in the ear (outer, middle, or inner) can cause hearing loss to a varying degree. For example, in conductive hearing loss, the loss is

caused by either obstruction or malformation of the auditory pathway. Common causes include earwax buildup, foreign objects, perforated eardrums, or infections like otitis media which can lead to fluid in the middle ear. Congenital abnormalities, such as microtia (underdeveloped outer ear) or ossicular malformations, and trauma to the ear, may contribute. CHL can often be treated or reversed through medical or surgical interventions, such as earwax removal, antibiotics, or corrective surgery. Unlike sensorineural hearing loss, which involves nerve damage, CHL typically results from mechanical obstructions and is often reversible.

Sensorineural hearing loss occurs when there is damage to the sensory cells (hair cells) in the cochlea or the auditory nerve pathways that carry sound signals to higher centres in the auditory pathway. The damage may be caused by factors such as aging (presbycusis), exposure to loud noises, genetic factors, ototoxic drugs, or infections. In SNHL, the hair cells in the cochlea or the auditory nerve fibres become damaged or degenerate, leading to a reduced ability to perceive sound or interpret sound signals. Unlike conductive hearing loss, which involves issues in the outer or middle ear, sensorineural hearing loss involves damage in the inner ear or auditory pathways, and it is typically permanent because the affected cells do not regenerate.

One of the common risk factors for hearing loss which can affect any age is noise exposure (Natarajan et al., 2023). Excessive or prolonged exposure to risk factors such as loud noise can lead to physical harm to the structures (e.g., hair cells) within the cochlea, decreased blood flow, and the presence of oxidative stress. As a result, the excessive stimulation of hair cells and auditory nerves leads to hair cell damage (Natarajan et al., 2023).

Presbycusis, also known as age-related hearing loss, impacts the peripheral auditory pathway through changes in the cochlea's mechanical sound transduction and the central auditory cortex through alterations in its connections (Shilling-Scrivo et al., 2021). The natural process

of neurodegeneration in the aging brain leads to age-related hearing loss (Bisogno et al., 2021). This includes the deterioration of the stria vascularis, loss of hair cells and primary afferent neurons, and changes in neurotransmitter release.

1.2.3. The impact of hearing loss

Hearing loss affect individuals with have it, and extends to their communication partners such as spouses, children, and friends (WHO, 2021). The severity and timing of hearing loss plays a significant role in determining its impact. For instance, severe-to-profound hearing loss in early childhood can result in difficulties with spoken language development, education, and reduce employment prospects (Lieu et al., 2020). On the other hand, hearing loss that occurs later in life due to aging or noise exposure may have a different impact.

The World Health Organization (2021) summarised the impact of hearing loss across three main levels: individual, family/communication partner, and economic (Table 1.4).

Table 1.4 Hearing loss/ deafness impact at three main levels: the individual, family/communicating partner, and economic impact (adapted from World report on hearing, WHO, 2021)

Level	Impact
Individual level	Listening and communication Education Language and speech Relationships Social isolation Relationships Cognition and mental health
Family/ communication level	Reduce social interaction Increase stress Reduce satisfaction within relationship
Economic level	Health sector Educational sector Social costs Loss of productivity costs

1.2.3.1. Impact at the individual level

The impact of hearing loss on an individual can vary according to age, with significant consequences for both children and adults. Children with congenital hearing loss typically experience delays in speech and language development, and despite improvements through interventions like hearing aids and cochlear implants, often face cognitive challenges, particularly in working memory and executive functions (Lieu et al., 2020). These difficulties can affect their educational and occupational outcomes; research shows that individuals with hearing loss are less likely to pursue higher education as stated by Lieu (2020). Additionally, hearing loss can negatively impact a child's quality of life, contributing to difficulties in social interactions, behavioural problems, and emotional well-being, with increased risks of internalising behaviours, conduct disorders, and psychiatric issues. Children with unilateral

hearing loss or cochlear implants may also experience vestibular problems that limit their ability to participate in everyday activities. Longitudinal studies have linked childhood hearing loss to lower self-esteem, anxiety, and depression later in life (Lieu et al., 2020). As individuals grow older, hearing loss can contribute to absenteeism from school, learning difficulties, and altered social interactions, with depression and anxiety commonly reported (Blazer et al., 2016). Anatomical changes in the brain, particularly in grey and white matter, help explain these effects; with hearing loss leading to structural changes in brain regions related to auditory and cognitive functions (Ratnanather, 2020). A comprehensive meta-analysis by Manno et al. (2021) revealed distinct neuroanatomical patterns between congenital and acquired hearing loss, showing that congenital cases exhibit greatest gray matter (GM) decreases in the right frontal lobe alongside pronounced white matter (WM) reductions beneath this region. In contrast, acquired hearing loss primarily affects GM volume in the insula and temporal auditory regions, with fewer studies systematically assessing WM changes in these cases (Manno et al., 2021). This aligns with Ratnanather's (2020) model linking hearing loss duration and onset timing to specific structural alterations in auditory-cognitive networks. While some studies report inconsistent localization of WM changes, congenital deficits consistently correlate with frontal lobe reorganization – likely reflecting compensatory neural plasticity during critical developmental periods – whereas acquired cases show stronger ties to insular atrophy from prolonged auditory deprivation.

Qualitative research has highlighted the isolation individuals with hearing loss experience, particularly in social settings and the workplace, leading to challenges such as fatigue, unemployment, and mental health issues (Heffernan et al., 2022).

1.2.3.2. Impact on family and communicating partner

The impact of hearing loss extends beyond the person to include those close to the person, such as partners, family members, and carers. Impact at this level includes communication

problems and isolation and decreases social interaction. Barker et al. (2017) conducted a qualitative meta-synthesis of the effects of hearing loss on both the person with hearing loss and their partner. They examined several databases and various concepts of hearing loss, such as mild-moderate hearing loss, hearing impairment, and deafness. Twelve studies were included in the analysis, which identified four main categories of impact (Barker et al., 2017). Firstly, hearing loss was found to lead to limitations in daily activities and restricted participation for both the person with hearing loss and their partner. Communication was also affected, resulting in reduced social interaction and negative effects on mood. The person with hearing loss often denied their hearing difficulties, and it was often the partner who prompted them to seek help. Secondly, the use of hearing aids had both positive and negative effects. While hearing aids were viewed positively by the communicating partner and allowed for the restoration of social activities (Manchaiah & Stephens, 2013), the person with hearing loss often experienced auditory fatigue, discomfort, and disappointment. This sometimes led to them abandoning the use of hearing aids. Thirdly, stigma and identity played a role in the adjustment process for both the person with hearing loss and their partner. The stigma associated with hearing loss and hearing aid use influenced decisions about accepting the condition and seeking help. Social identity also affected how the stigma was perceived, with positive attitudes from others normalising the use of hearing aids, while negative opinions from the partner acted as a barrier to seeking help. Coping strategies were also identified, with some individuals accepting their condition and adjusting to it, continuing with activities despite limitations, and using effective communication strategies to overcome challenges.

In conclusion, hearing loss has an impact beyond the individual with hearing loss, affecting their communicating partner and other family members.

1.2.3.3. Economic impact

In terms of the economic impact of hearing loss, there are two ways hearing loss can manifest. The first is through direct impact, which refers to the expense incurred by the person with hearing loss for assessments, treatments, and aural rehabilitation. This includes costs of hearing aids, cochlear implants, batteries, and hospital visits. The second is through indirect costs, which result from the time lost due to these interventions and the loss of labour/productivity. This includes sick leave and unemployment (Huddle et al., 2017).

The medical cost of hearing loss is high (Wells et al., 2020; Huddle et al., 2017; Deniz et al., 2022). Huddle et al. (2017) reviewed data from 25 reports on the direct and indirect economic impact of hearing loss in the USA and globally. They found that the economic impact of hearing loss could be measured either as a disability, a medical expenditure, a cost estimate, or as work-related or noise-induced hearing loss (Huddle et al., 2017). For example, loss of productivity due to hearing loss is estimated annually to be $1.8-$1.94 billion in the USA alone and the excess medical costs are estimated to total $3.3-$12.8 billion. In Australia, the total cost of cochlear implants was estimated to be $32.8 million in 2017 ($59, 942 per person) as per Hearing Care Industry Association: HCIA (HCIA, 2017).

Work related economic impact of hearing loss can arise in the form of increased unemployment, which was reported commonly in late onset hearing loss in adults that occurs later in life (Shan et al., 2020). This can be manifested as an increase of sick leave due to stress caused by the work environment leading to loss of productivity (Kramer et al., 2006).

In summary, hearing loss impacts individuals, families, and society in various ways. For individuals it can cause developmental delays, cognitive difficulties, and emotional challenges. In children it can affect education, social interactions, and mental health. Families and partners face communication barriers and emotional strain, while the economic burden includes both direct costs (e.g., treatments, devices) and indirect costs (e.g., lost productivity,

unemployment). Overall, hearing loss has far-reaching effects, highlighting the need for early intervention and support.

1.2.4. Clinical management of hearing loss and deafness

The assessment of hearing loss begins with a comprehensive history and clinical examination, followed by an audiological assessment as recommended by NICE (2018) & BSA (2021).

A thorough history should include information about the onset of hearing loss (whether sudden or gradual), any associated symptoms such as tinnitus or hyperacusis, the individual's cognitive abilities, and any psychological difficulties related to hearing. It is important to inquire about the individual's preferred mode of communication and to identify any communication challenges they may be experiencing at home, work, or during social interactions. Audiological assessment should include otoscopy for impacted wax or diseases of the outer ear, pure tone audiometry to assess hearing level, and tympanometry for middle ear diseases.

Immediate referral is necessary in certain instances of hearing loss, such as sudden onset or rapid deterioration of hearing within a 72-hour period, whether it affects one or both ears. Referral is also warranted for persistent tinnitus that is unilateral, pulsatile, and causing disruptions to sleep patterns, as well as when it is associated with anxiety or depression (BSA, 2021).

The management of hearing loss depends on the severity of the condition. Individuals with any degree of hearing loss should have a conversation about their pure tone audiogram results and how hearing loss affects their communication (NICE, 2018). They should also be informed about different management options available (hearing aids, assistive listening devices, and communication strategies) and the advantages and disadvantages of each option.

In this thesis, I will focus on discussing deafness and severe-to-profound hearing loss in more detail.

The objective of hearing rehabilitation in deaf and severe-profound hearing-impaired adults is to enhance quality of life by reducing the deficits caused by hearing loss. This is accomplished through a combination of sensory management, instructions, perceptual training, and counselling (Boothroyd, 2007). Sensory management aims to improve auditory function by providing hearing aids, cochlear implants, or other assistive listening devices with instructions on using technology and controlling the listening environment. Other facets of care include perceptual training focuses on improving speech perception by providing auditory or lipreading training and communication, and counselling to help individuals cope with the emotional and practical aspects of their hearing loss.

Hearing aids and cochlear implants enable individuals to hear, they do not completely restore hearing. Figures 1.6 and 1.7 illustrate both hearing restoration devices (hearing aid and cochlear implant).

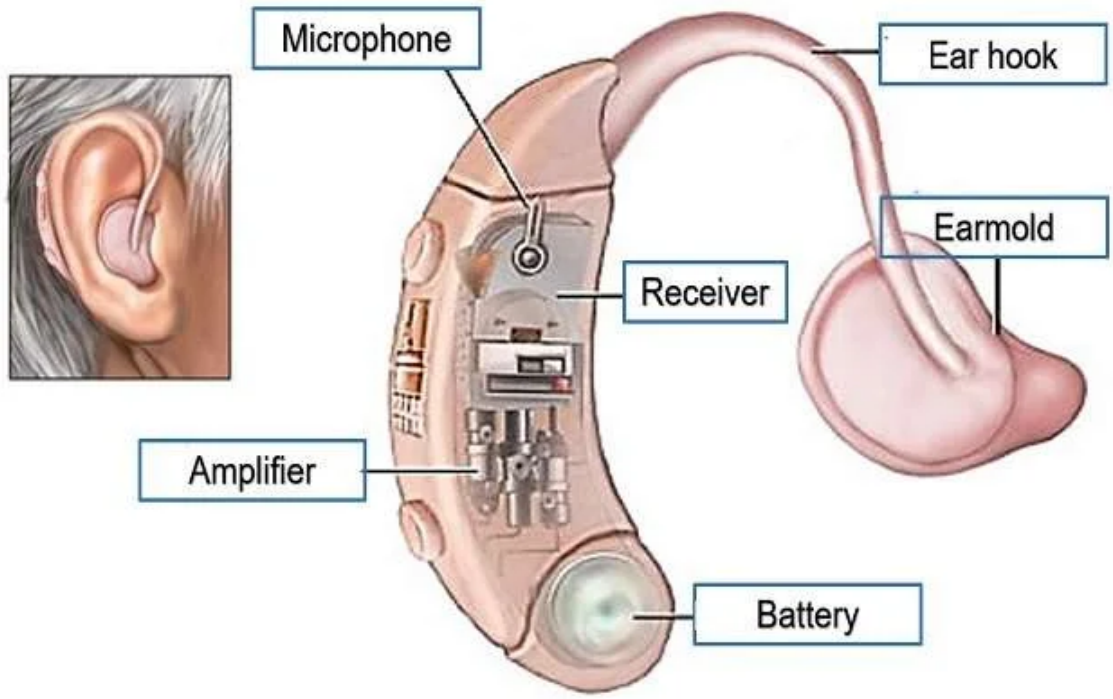


Figure 1.7 Hearing aid components: microphone (captures sound), amplifier (processes and enhances signals), receiver/speaker (delivers amplified sound), and power source (battery). Image adapted from https://baslpcourse.com/hearing-aid-ha-and-its-components/.

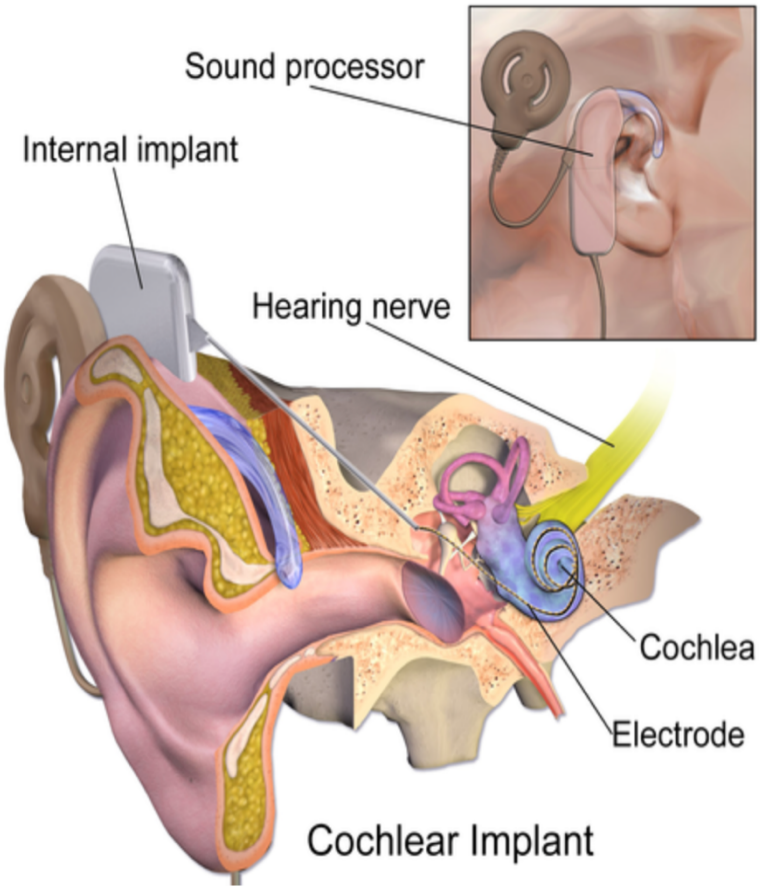


Figure 1.8 Cochlear implant components: External part includes a sound processor (with microphone) and headpiece with magnet; internal part consists of a receiver coil, electronics package, and electrode array surgically implanted in the cochlea. Adapted from Blausen.com Staff (2014).

Hearing aids amplify sound vibrations, while cochlear implants use electrical stimulation to facilitate hearing (NICE, 2019). A cochlear implant consists of an external component and an internal component. The external processor is connected to the surgically implanted internal part, which contains electrodes that stimulate the spiral ganglion cells connected to the auditory nerve fibres. Sounds are gathered by the external sound processor and translated into electrical signals by the internal component.

For Deaf individuals and those with severe-to-profound hearing loss, compression parameters should be introduced when providing hearing aids to improve the audibility of speech and minimise distortion of usable speech cues (Turton et al., 2020). Furthermore, the use of multichannel wide-dynamic range compression is recommended to ensure audibility and comfortable loudness in different environments and across various speech and sound levels.

According to the NICE (2019), adults in the UK with severe-to-profound hearing loss who do not benefit from hearing aids may be recommended for a unilateral cochlear implant (NICE, 2019). It is not recommended to undergo a bilateral cochlear implantation in adults as it could worsen or induce tinnitus, despite positive auditory outcomes as stated by NICE (2019). According to a review by Farinetti (2014), tinnitus is more commonly seen as a complication after implant surgery in adults than in children. This was shown in a retrospective analysis of postoperative complications in cochlear implant patients, including both children and adults who were implanted between 1993 and 2013 (Farinetti et al., 2014). The study included 403 patients (168 adults and 235 children). The postoperative complications were categorised as major (requiring hospitalisation) or minor (managed conservatively). The overall percentage of complications was 19% (n=80), with 5% (n=20) being major complications and 14.9% (n=60) being minor complications. Among the minor complications, tinnitus was reported by seven adults, while no children reported experiencing tinnitus.

Recommendations for cochlear implant candidacy vary significantly across countries and have evolved over time. These variations include differences in criteria for bilateral implantation and the use of cochlear implants for individuals with single-sided deafness. Van de Heyning et al. (2022) identified several factors contributing to this variation. Firstly, there is a lack of standardised guidelines for referrals, leading to inconsistent and insufficient referrals. Secondly, there is a lack of knowledge among medical professionals and the general public with respect to hearing loss awareness and referral guidelines. Lastly, there is a lack of

consensus on the criteria for determining eligibility for cochlear implantation. This variability is also influenced by funding models, with countries like Australia, Germany, and Italy having more flexible criteria, while countries like the UK and Belgium have stricter criteria (Van de Heyning et al., 2022).

Guidelines for cochlear implants in Saudi Arabia vary depending on the institution, and each centre has the autonomy to adjust its preferences and judgments (Alzahrani et al., 2021). Generally, cochlear implantation for adults is recommended in the case of (1) post-lingual bilateral severe sensorineural hearing loss with hearing thresholds exceeding 70 dB hearing level (HL) in conversational frequencies (1-4 kHz), (2) limited or no improvement in hearing with properly fitted hearing aids, as indicated by aided thresholds or poor word recognition scores in the best aided condition, and (3) no contraindications for surgery, such as damage to the vestibulocochlear nerve.

Bimodal hearing, where one ear is electrically stimulated by cochlear implant and the other ear receives amplified sound from a conventional hearing aid is a common practice among severe-to-profoundly adults (Neuman et al., 2017; Devocht et al., 2020). In a study conducted by Devocht et al. (2020), a group of 26 participants who had cochlear implants and regularly used a hearing aid in the opposite ear were asked to complete a daily life questionnaire. The questionnaire assessed factors such as bimodal hearing aid use, hearing disability, hearing handicap, and general quality of life. These participants were compared to a group of 22 cochlear implant participants who did not use a contralateral hearing aid. The study found no significant difference between the two groups. However, participants who used both a cochlear implant and a hearing aid (bimodal hearing) reported improved performance in various listening situations such as understanding speech in quiet environments and identifying sounds.

In conclusion, providing auditory rehabilitation for adults who are deaf or have severe-to-profound hearing loss is a complex process. Ultimately, it is the patient's decision to choose between hearing devices such as hearing aids or cochlear implants, based on a thorough understanding of their benefits and disadvantages. Despite the limited research characterising the effects of bimodal hearing, it is recommended that this option be offered to patients with severe-to-profound hearing impairments, as it may provide additional auditory benefits.

1.3. Tinnitus

1.3.1. Definitions, categories, and prevalence

Tinnitus is derived from the Latin verb *tinnire* meaning "to ring," and is defined as the perception of sound without an external acoustic stimulus (Langguth et al., 2013). It is considered a symptom rather than a disease and its impact varies among individuals, leading to differences in definitions, clinical guidelines, and impact. To aid researchers and clinicians, definitions have been established to distinguish between the experience of tinnitus with and without associated emotional, cognitive, and functional difficulties (De Ridder et al., 2021). According to these definitions, *Tinnitus* is *the conscious awareness of a tonal or composite noise for which there are no identifiable corresponding external sound sources*, whereas *Tinnitus disorder* is *the conscious awareness of a tonal or composite noise for which there are no identifiable corresponding external sound sources, associated with emotional and/ or cognitive dysfunction, and/or autonomic arousal leading to behaviour changes and functional disability*.

There are many ways to classify tinnitus (Figure 1.9).

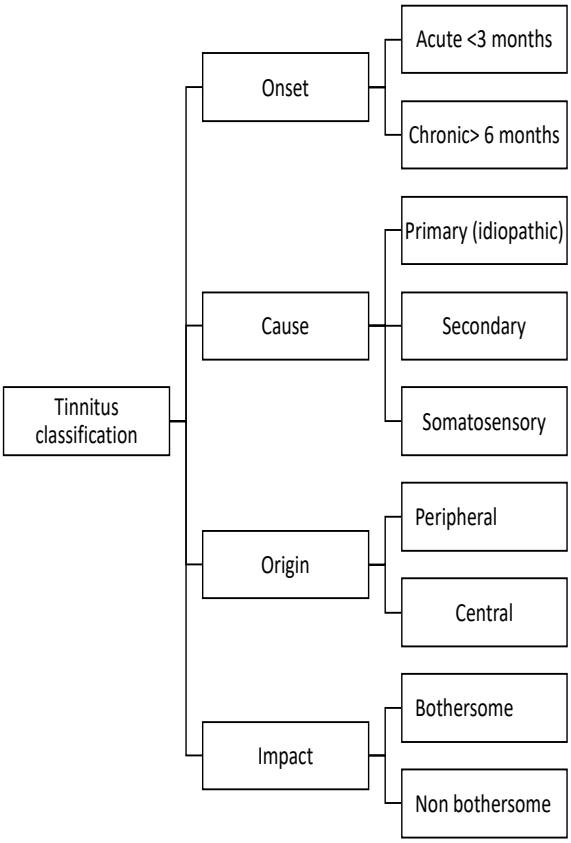


Figure 1.9 Tinnitus classification based on onset, aetiology, origin, and psychosocial impact. Adapted from Tunkel et al. (2014).

Tinnitus can be described as acute (tinnitus onset in less than 3 months) or chronic (tinnitus lasting 6 months or more) (Langguth et al., 2018). The cause of tinnitus can be primary, also termed idiopathic (often associated with hearing loss but can be with no hearing loss involvement), or secondary (due to an organic cause) (Tunkel et al., 2014). Primary tinnitus is also called subjective tinnitus which indicates that the tinnitus sound can only heard by the patient. Somatic or somatosensory tinnitus is another example of subjective tinnitus that occurs or changes in quality because of a specific body movement such as jaw clenching or eyes turning, or by applying pressure to the head or neck (Han et al., 2009a). Secondary tinnitus can also be called objective tinnitus which is defined as a tinnitus sound that can be

heard by the patient and by an examiner (Langguth et al., 2013), e.g., pulsatile tinnitus caused of a carotid bruit can be heard by an examiner through auscultation.

The prevalence of tinnitus varies significantly across countries due to differences in how it is defined, measured, and assessed in studies. Additionally, tinnitus prevalence varies among different populations, such as adults and children, those with hearing loss and those with normal hearing, and younger and older individuals. For instance, a systematic review was conducted to estimate tinnitus prevalence worldwide, but the specific question used to ask about tinnitus varied among the studies included in the review (McCormack et al., 2016). Some studies asked whether participants experienced tinnitus lasting for more than 5 minutes at a time, while others asked whether they had experienced bothersome tinnitus in the past year. This variability in questioning methods contributes to the variation in reported prevalence rates. Moreover, most prevalence data is derived from studies conducted in Western countries, particularly North America and Europe. For example, between 2017-2018, a survey called the pan-European Tinnitus Survey was conducted to determine the prevalence of tinnitus in several European countries (Biswas et al., 2021). The survey used a standardised set of questions and responses. For example, participants were evaluated for the occurrence of tinnitus (any tinnitus) by asking if they have experienced sounds in their head or ears lasting more than 5 minutes. To assess tinnitus severity, participants were asked about the level of worry, annoyance, or discomfort caused by these noises during their most severe episodes. Results showed that the prevalence of any tinnitus was 14.7%, with the highest prevalence being in Bulgaria (28.3%) and the lowest in Ireland (8.7%). The prevalence of severe tinnitus was 1.2%, with the highest prevalence being in Romania (4.2%) and the lowest in Ireland (0.6%). It was found that one in seven adults in the European Countries had tinnitus.

A review conducted by Jarach et al. (2022) estimated the worldwide prevalence and incidence of tinnitus in the general population (Jarach et al., 2022). The study included data from 113 records published between 1971 and 2021, consisting of 83 prevalence studies and 12 incidence studies. Most studies (35) were conducted in Europe, followed by North America (9) and Asia (7). The review considered both any tinnitus and severe tinnitus in its analysis. The prevalence for any form of tinnitus was 1,164 per 100,000 individuals per year. The prevalence of chronic tinnitus was found to be 9.8%, while severe tinnitus had a prevalence of 2.3%. The study also discovered that the prevalence of tinnitus increased with age, with rates of 9.7% among adults aged 18-44 years, 13.7% among adults aged 45-64 years, and 23.6% in individuals older than 65 years. There was no significant difference in prevalence between genders. The study findings suggested that tinnitus has a significant global burden comparable to that of pain and migraine. Further research in this area is needed to better estimate its global burden and address this issue to enhance tinnitus research.

After the Coronavirus Disease (COVID-19) outbreak in March 2020 and the subsequent introduction of multiple vaccines, several patients have reported experiencing tinnitus that could be attributed to either the disease itself or the administration of the vaccine. To examine the likelihood of occurrences, paper reviews, clinical observations, and cohort studies were conducted. In Saudi Arabia, 407 patients diagnosed with COVID-19 were included in a study that investigated tinnitus as a complication of the virus (Amoodi et al., 2023). These patients were interviewed over the phone and asked about six otological symptoms: hearing loss, tinnitus, vertigo, dizziness, imbalance, and ear fullness. The age of the patients included in the study was 18 years and older, and females made up approximately 53.7% (n=218) of the sample. The study found that dizziness and vertigo were the most commonly reported symptoms, affecting 34% (n=140) of the cases. Ear pain was reported by 13.1% (n=53) of the patients, while tinnitus was reported by 12.1% (n=43). There was a higher prevalence of

tinnitus in females (n=32, 16%) than males (n=17, 12.7%). In total, tinnitus prevalence studies in Saudi Arabia have been limited in scope and sample size, potentially leading to less accurate estimates.

A similar study was conducted in Germany, but with a larger sample size of 1082 adults who had experienced long Covid (Degen et al., 2022). These patients were approached through online surveys and were included in the study if they were 18 years or older and had symptoms persisting for more than 4 weeks after a confirmed SARS-CoV-2 infection, as indicated by a self-reported positive test. Participants were asked if they had experienced dizziness, vertigo, and tinnitus after their infection, and were asked to rate the severity of their symptoms on a scale from 0-10, with scores of 8 or higher considered severe symptoms. The study found that 72.9% of the survey respondents were female, and 50% of the patients had been fully vaccinated prior to their infection. Of the patients, 647 (59.8%) reported experiencing dizziness and vertigo, followed by tinnitus in 332 patients (30%), and a combination of all three symptoms in 266 patients (24.6%).

Over a span of 13 months after the implementation of COVID-19 vaccines in the United States, an institution noted the occurrence of tinnitus in individuals who had been vaccinated (Lin & Selleck, 2023). The study included patients who received COVID-19 vaccines (Pfizer, Moderna, or Janssen) between December 1, 2020, and December 31, 2021, and had a diagnosis of tinnitus, an audiogram, and at least one visit to an Otolaryngological clinic. Of 1,254 patients, 27 met the inclusion criteria, consisting of seven males and 20 females. The study found that 16 patients developed tinnitus after receiving the Pfizer vaccine, seven after receiving the Moderna vaccine, and four after receiving the Janssen vaccine. However, due to the small sample size, the study was unable to establish a correlation and recommended following common guidelines for treating tinnitus or any associated otological symptoms,

such as sudden hearing loss or vertigo. A higher proportion of females than males reported tinnitus.

1.3.2. Tinnitus risk factors, pathophysiology, and models

To better understand the pathogenesis of chronic tinnitus, it is essential to address the related risk factors such as hearing loss, exposure to noise, and aging. These factors can either occur independently or in combination over time, ultimately leading to the development of tinnitus. It is crucial to acknowledge that the development of acute and chronic tinnitus differs, and while acute tinnitus may progress to chronic tinnitus, this thesis will solely concentrate on chronic tinnitus.

The development of tinnitus is often associated with hearing loss (Goderie et al., 2022; Stohler et al., 2019). People with tinnitus and hearing loss are often more troubled than those with tinnitus and normal hearing (Spankovich et al., 2018; Goderie et al., 2022). Godere (2022) conducted a prospective cohort study to investigate the risk factors associated with new-onset tinnitus. The study followed 734 participants with normal hearing, as determined by the "National Hearing Test: a screening test examine the ability to hear speech in noise" and no pre-existing tinnitus. Participants were assessed three times: at baseline (T0), 5 years (T1), and 10 years (T2), from 2006 to 2016. Among these participants, 99 developed tinnitus at T1, and 38 developed tinnitus at T2. The study identified difficulties in speech perception in noisy environments (hearing difficulties) and anxiety as significant risk factors for developing new tinnitus. Furthermore, the study found that individuals with hearing loss were more likely to be bothered by tinnitus than those with normal hearing. This study is supported by the findings of two previous studies conducted by Sindhusake (2003) and Henry (2015), which also found a correlation between tinnitus and more severe hearing loss (Henry et al., 2015; Sindhusake et al., 2003). Henry et al. (2015) noted the importance of conducting separate hearing screenings for individuals with tinnitus, as many patients who report being

bothered by their tinnitus are actually conflating it with being bothered by the symptoms of their hearing loss.

Hearing loss may not be detectable on a hearing test, but it can be characterised by challenges in hearing, particularly in noisy settings, as well as persistent tinnitus (Spankovich et al., 2018). In a study conducted by Spankovich, a cross-sectional population-based study, it was found that out of 2015 participants who met the criteria for normal hearing on pure tone audiometry at 0.5, 2.0, and 4.0 kHz with a threshold of less than or equal to 25 dB HL, 265 individuals (13%) reported hearing difficulty, and 10.6% reported persistent tinnitus. Hidden hearing loss is frequently mentioned as an area of interest, particularly in animal studies (Liberman, 2020; Kujawa & Liberman, 2015). Extensive research conducted by Liberman in animal studies explored this theory, concluding that the loss of hair cell synapses in auditory nerve fibres leads to a lack of spontaneous activity or response to sound. As a result, there is a significant increase in hyperactivity in the central pathway, ultimately causing tinnitus.

Exposure to loud noises poses a notable risk for the development of tinnitus (Hickman et al., 2018; Llano et al., 2012; Roberts et al., 2010; Shore et al., 2016; Shore & Wu, 2019). Exposure to noise can have a wide-ranging effect on the auditory system, even if a person's hearing appears to be normal on standard threshold tests. This impact may not be immediately evident on threshold tests, but it can manifest as tinnitus, a symptom often linked to noise exposure. Hickman (2018) suggested that individuals exposed to loud noise, such as military personal, may develop persistent tinnitus, even if their pure tone audiogram indicated normal hearing. This finding was supported by Hickman et al. (2018) who exposed anesthetised chinchillas to an explosive-like impulses with a peak pressure of 160-175 dB SPL. The study involved testing cochlear dysfunction and histopathology. Although there was a temporary threshold shift of over 40 dB, there was no permanent threshold shift or loss of hair cells. However, there was a loss of 20-45% of synapses pointing to elements of

synaptopathy (Hickman et al., 2018). A study conducted by Llano et al. (2012) investigated the development of chronic tinnitus in older mice (30 months) who were exposed to noise at a younger age (1-3 months). The mice were tested and those that showed signs of hearing loss and tinnitus were later examined behaviourally. The study found that the auditory cortex of mice who developed tinnitus and hearing loss were affected by the noise exposure. This study suggested age might also cause a drop in the cortical GABAergic transmission; the primary inhibitory neurotransmitter found in the central nervous system (Llano et al., 2012).

Tinnitus is also associated with changes at a cellular level as shown in animal studies (Shore et al., 2016; Shore & Wu, 2019). Animals that showed behavioural signs of tinnitus were found to also show an increase in the distribution of glutamatergic inputs from the cochlear source to the cochlear nucleus. However, there was no change in this distribution in the animals that did not show behavioural signs of tinnitus. Additionally, there was an observed increase in the spontaneous firing rate and cross-unit synchrony of fusiform cells in the dorsal cochlear nucleus in animals that showed behavioural evidence of tinnitus, compared to those that did not.

The likelihood of experiencing tinnitus increases with age (Deklerck et al., 2020; Nondahl et al., 2010; Shargorodsky et al., 2010; Sindhusake et al., 2003; Stohler et al., 2019). A large study was conducted to investigate the prevalence and characteristics of tinnitus in adults aged 55-99 years (Sindhusake et al., 2003). The study included 2,015 participants and gathered detailed hearing history and examination data. Tinnitus was assessed by asking participants if they had experienced prolonged ringing, buzzing, or other sounds in their ears or head in the past few years. The study found that 30% of participants (602 individuals) developed tinnitus, with the highest reporting occurring in the 60-69 age group, followed by those younger than 60. Additionally, the study found that individuals who reported tinnitus also had worse hearing loss at both lower and higher frequencies than those who did not have

tinnitus. Similarly, Shargirodsky (2010) & Stohler (2019) found tinnitus was more prevalent in the age group 60-69 years old.

Several studies have found no significant differences in the prevalence of tinnitus between males and females (Deklerck et al., 2020; Sindhusake et al., 2003; Stohler et al., 2019). The literature has frequently explored the relationship between smoking and tinnitus, finding a strong positive correlation (Durazzo et al., 2010; Goderie et al., 2022; Veile et al., 2018). A systematic review of German epidemiological studies aimed to determine whether smoking was a risk factor for tinnitus development (Veile et al., 2018). The review included 20 studies of various types, such as cross-sectional and cohort studies. The odds ratios of developing tinnitus for current and former smokers and those who had ever smoked were 1.21, 1.13, and 1.2, respectively, and all were statistically significant. While this study recognised smoking as a risk factor, it did not establish the mechanism by which smoking can cause tinnitus due to multiple, confounding factors such as cardiovascular disease, which is also frequently caused by smoking. A further cohort study followed participants without tinnitus for 5 to 10 years and found that smokers had a higher risk of developing tinnitus (odds ratio of 1.5) (Goderie et al., 2022). This study aligned with other cohort studies but also did not provide insight into the pathogenesis of smoking in tinnitus development. Furthermore, the study identified that factors unrelated to the ear, such as anxiety, depression, and somatisation, were also significantly associated with the onset of tinnitus.

The challenge in identifying risk factors for tinnitus is that not everyone with hearing loss or exposure to high levels of noise develop the condition. This suggests that factors beyond auditory damage contribute to tinnitus onset. Advances in animal studies and imaging techniques have significantly deepened our understanding of tinnitus (Haider et al., 2018; Hu et al., 2021; Kaltenbach, 2011; Khan et al., 2021; Lanting et al., 2009). These studies have revealed changes in both central auditory and non-auditory brain regions in tinnitus

(Galazyuk et al., 2012; Hu et al., 2021; Langguth et al., 2018). Hyperactivity in various parts of the auditory pathways—ranging from the cochlear nuclei to the inferior colliculus, and up to the primary and secondary auditory cortex—has been observed (Galazyuk et al., 2012; Hu et al., 2021). In addition, features such as bursting and synchronised neural activity, and reorganisation of cortical tonotopic maps, are evident (Galazyuk et al., 2012).

The involvement of non-auditory brain regions, particularly the limbic system, in tinnitus is well-documented. The limbic system is involved in emotion and memory, and plasticity within this circuit is thought to contribute to the generation and persistence of tinnitus (Galazyuk et al., 2012; Haider et al., 2018; Hu et al., 2021). However, these findings remain inconclusive, and larger-scale studies are needed to confirm these patterns.

To address these complexities, several theoretical models have been proposed to explain the origins and persistence of chronic tinnitus. These models highlight the involvement of non-auditory brain structures, particularly the limbic system and autonomic nervous system, in the perception and maintenance of tinnitus. Despite differences, these models share common theoretical perspectives on the multifactorial nature of tinnitus.

a) Psychological habituation model

One of the earliest models of tinnitus was proposed by Hallam and colleagues and explored the selective functioning of the central auditory system and the influence of attention (Hallam et al., 1984). In a normal state, the brain habituates to repetitive stimuli, including tinnitus, leading to a decrease in perception of the stimuli over time. However, when this habituation process is impaired, the central auditory system focuses on the tinnitus stimuli, and the autonomic nervous system becomes aware, resulting in the perception of tinnitus. Habituation can be impaired when the nature of tinnitus changes, such as the emergence of new tinnitus.

Additionally, psychological distress, such as that caused by stress, can also impair habituation (McKenna, 2004).

b) Neurophysiological model

In the neurophysiological model, the involvement of non-auditory structures such as the limbic system, reticular formation, and the autonomic nervous system play a significant role in the activation and persistence of tinnitus (Jastreboff 1990, Jastreboff & Hazell, 1993). Through extensive animal research, Jastreboff developed a model that consists of three main components (Jastreboff & Hazell, 1993).

- Component 1 is the generation of tinnitus: Tinnitus sounds are typically produced in the peripheral auditory system, although in some cases they may originate in the central auditory system. The majority of tinnitus cases are linked to disorders or damage in the cochlea or cochlear nerve.
- Component 2 involves detection of tinnitus sound: The subcortical level is responsible for detecting tinnitus through pattern recognition. This refers to the central auditory system's capability to extract signals based on certain criteria. This allows for the detection of significant sounds while disregarding non-essential or unrelated ones.
- Component 3 is the perception and evaluation of tinnitus: The sound is then evaluated by the auditory cortex, with the involvement of the limbic system and other structures like the prefrontal cortex.

As a result of Jastreboff's model, Tinnitus Retraining Therapy (TRT) was developed (Jastreboff & Jastreboff, 2003). This therapy involves identifying patients who experience significant distress due to tinnitus and providing them with personalised treatment options. The TRT comprises directive counselling (education) and part sound therapy with or without an instrument such as hearing aid(s) or sound generator.

c) Fear-avoidance model

The fear-avoidance model is based on a model from chronic pain that proposes that pain perception consists of a sensory component (pain sensation) and an emotional component (Lethem et al., 1983). The emotional component of the pain model is further divided into the pain experience, pain behaviour, and the physiological response to pain. In the context of chronic pain, the model focuses on the emotional component, specifically the pain experience and pain behaviour. Based on the model, individuals experiencing chronic pain will choose between a confrontational or avoidance coping strategy. Those who adopt a confrontational response acknowledge the pain as temporary, are driven to resume normal activities, and are willing to overcome personal pain barriers as the underlying cause resolves naturally or through conservative treatment or surgery.

In contrast, the avoidance response, which is seen as maladaptive, involves individuals being motivated to avoid any potential pain triggers due to fear. In the tinnitus model, when tinnitus increases in volume, it can result in negative thoughts about tinnitus and its effects, fear associated with tinnitus, and ultimately the avoidance of situations linked to tinnitus (Kleinstäuber et al., 2013, Cima et al., 2018).

Cima et al. (2018) examined the impact of tinnitus-related fear on tinnitus distress in adults receiving cognitive-behavioural therapy (CBT) for tinnitus. The study was a randomised controlled trial with 492 tinnitus patients. Participants were divided into two groups: one group received usual care (UC) in the form of counselling and sound therapy upon request, while the other group received standard care (SD) in the form multidisciplinary audiological and psychological diagnostics approach. Both groups were monitored over a period of one year. Outcomes were assessed using the Tinnitus Questionnaire (TQ; Hallam, 2009), the Tinnitus Handicap Inventory (THI, Newman et al., 1996) and a newly developed Fear of Tinnitus Questionnaire (FTQ; (Cima et al., 2011) designed to measure tinnitus-related fear. A

mediator model was used to assess the role of tinnitus-related factors as mediators, assuming the effect of treatment (UC or SD) on the final outcome was mediated by tinnitus-related fear. The findings indicated that CBT was more effective in reducing tinnitus-related fear compared to usual care (Hallam, 2009)

d) Cognitive Behavioral Model

The Cognitive Behavioural Model of tinnitus is based on clinical observations and previous models used to describe conditions such as anxiety, chronic pain, and insomnia. Research has found that individuals often misinterpret tinnitus as a serious physical illness (McKenna et al., 2014).When people become aware of their tinnitus, it can lead to negative thoughts and distort their perception of its loudness. As a result, they may overestimate the severity of their tinnitus, which starts a cycle of increased attention and monitoring that reinforces their perception of the sound and triggers more negative thoughts. Handscomb et al. (2020) tested this model on a sample of individuals who have been experiencing tinnitus for more than two months. To examine each aspect of the model, seven different tools were utilised Click or tap here to enter text.. The Tinnitus Cognition Questionnaire (TCQ; Wilson & Henry, 1998) as used to evaluate the content and frequency of negative automatic thoughts related to tinnitus. Arousal and emotional distress were assessed using the Clinical Outcome in Routine Examination Evaluation (CORE; Evans et al. 2000). The Tinnitus Vigilance and Awareness Questionnaire (TVAQ; Cima et al., 2018) was employed to measure selective attention and monitoring. The Tinnitus Fear Avoidance Scale (TFAS; Kleinstäuber et al., 2013) was utilised to assess safety behaviours. The Modified Illness Perception Questionnaire (IPQ-M;Moss-Morris et al., 2002) was used to gauge beliefs about tinnitus. The Tinnitus Magnitude Index was employed to determine distorted perception. Finally, the Tinnitus Reaction Questionnaire (TRQ; Wilson et al., 1991)was utilised to evaluate tinnitus-related distress, and it was the outcome variable. Data from 342 participants were analysed. Several

models were examined, and the end results showed that most of the components of the Cognitive Behaviour model were correlated with the exception of beliefs (it was considered as an exogenous variable with weak correlation between TRQ and IPQ-M (Handscomb et al., 2020).

e) Neuro-mechanical framework of tinnitus

The neuro-mechanical framework of tinnitus proposes that tinnitus is best conceptualised as a dimensional disorder, characterised by a complex interplay of behavioural, biological, and neurophysiological phenotypes, rather than trying to categorise it into subtypes (Mohan et al., 2022). The proof of concept for this neuro-mechanical framework considers four key factors (1) Age, duration, and onset of tinnitus, (2) Hearing ability, (3) Tinnitus severity in terms of loudness, and (4) The emotional aspect of tinnitus severity. However, empirical evidence is needed to support the use and validity of this approach to understanding and managing tinnitus.

1.3.3. Tinnitus impact

The distress caused by tinnitus is more closely associated with the psychological state of the patient rather than the psychoacoustic characteristics such as its pitch and loudness of the tinnitus sound (Brüggemann et al., 2016; Han et al., 2009). Tinnitus can negatively impact one's quality of life in many ways. For example, insomnia and tinnitus severity have a positive correlation, as the constant presence of tinnitus sounds can make it difficult to fall asleep or stay asleep, leading to sleep disturbances (Folmer & Griest, 2000; Gallo et al., 2023; Stohler et al., 2019). The pathophysiological basis for this could be explained by the neuroanatomical changes associated with chronic tinnitus. Lan et al. (2020) examined brain activity in acute and chronic tinnitus suffers using high-density electroencephalography (EEG) to identify functional areas associated with the perception of tinnitus (Lan et al.,

2021). Acute tinnitus was associated with reduced activity in the superior frontal cortex and increased gamma-band activity in the middle frontal and parietal regions. Chronic tinnitus showed decreased activity in the superior frontal cortex at beta and gamma frequencies, but increased activity in the inferior frontal cortex and superior temporal cortex. Additionally, chronic tinnitus was associated with increased cerebral blood flow in key brain areas and enhanced connectivity between regions such as the parahippocampus and posterior cingulate cortex. In contrast, acute tinnitus was associated with reduced connectivity between auditory and non-auditory brain regions. These changes suggest that tinnitus involves dynamic shifts in brain function, which may contribute to its persistence. Hence, it can explain the associated comorbidities commonly seen with tinnitus patients including sleeping difficulties and an inability to relax. Moreover, tinnitus can also cause anxiety and stress, which further contribute to sleep difficulties (Goderie et al., 2022).

Depression is commonly occurring comorbidity in tinnitus patients (Stohler et al., 2019; Zhang et al., 2023). The precise relationship between depression and tinnitus remains uncertain, with most studies focusing on determining the prevalence of depression in tinnitus patients or vice versa, rather than exploring or elucidating a causal link between the two conditions.

A study by Goderie et al. (2022) found a correlation between somatisation and the onset of tinnitus. It is evident that individuals experiencing tinnitus for the first time may exhibit symptoms that are disproportionate to their condition (Goderie et al., 2022). Therefore, it is crucial for a clinician to assess individuals who experience tinnitus for the presence of these psychological conditions and provide appropriate referrals if necessary.

Tinnitus can have a negative impact on an individual's ability to work, leading to absences and decreased productivity (Bhatt et al., 2017; Trochidis et al., 2021). A systematic review included five studies that examined the healthcare and social costs associated with tinnitus

(Trochidis et al., 2021). These studies were conducted in the USA, Netherlands, and UK, with all costs reported in Euros. For instance, in the USA, the annual cost for patients with tinnitus attending a local clinic was estimated to be EUR 564 per patient for clinical visits. One of the included studies was a randomised controlled trial focused on the cost-effectiveness of CBT compared to usual tinnitus care (Cima et al., 2012). This study identified four main cost categories: healthcare cost, patient and family costs, productivity loss, and total annual cost. For usual care, the annual healthcare cost was estimated to be around EUR 3,300, while CBT cost EUR 3,429. Patient and family costs for usual care were approximately EUR 115, compared to EUR 90 for CBT. Productivity loss for usual care was estimated to be around EUR 2,565, and EUR 2,764 for CBT. The total annual cost for usual care was EUR 5,980, while for CBT it was EUR 6,283. The study found that there is a significant financial burden caused by both direct and indirect healthcare costs. There is a need for more recent research to investigate the updated economic impact of tinnitus on individuals and society, with more studies conducted globally.

Based on previous research, tinnitus is frequently linked to several psychological conditions like depression, anxiety, and sleep problems. Therefore, a comprehensive assessment of tinnitus by healthcare professionals should include an assessment of those comorbidities to determine the patient's needs and the best management strategy. Additionally, organisations and government entities should take into consideration the financial burden of tinnitus and tinnitus treatment in order to provide necessary solutions and assistance.

1.3.4. Tinnitus management

The initial step in managing tinnitus involves providing counselling and education to the patient. This helps alleviate the patient's stress and allows them to understand the possible causes of tinnitus, enabling them to accept the available management approaches (BSA, 2020, Erlandsson et al., 2020). Tinnitus severity assessment and identifying any associated

comorbidities can be assessed with the use of validated tinnitus questionnaires such as Tinnitus Questionnaire; TQ (Hallam, 2009), Tinnitus Handicap Inventory; THI (Newman et al., 1996a), and Tinnitus Functional Index; TFI (Meikle et al., 2012).The use of these questionnaires can help in determining the impact of tinnitus and provide a referral for those who need psychological support (Cima et al., 2019, NICE, 2020).

When tinnitus is associated with hearing loss, the use of hearing aids and cochlear implants can be helpful in improving the condition. However, according to NICE guidelines, there is a lack of research on how to effectively manage tinnitus in patients who are deaf or have a severe-profound hearing loss, and there is no available tinnitus questionnaire tailored to their need (NICE, 2020). Therefore, certain management approaches may not be applicable in this specific category of patient. For example, the provision of hearing aids is recommended as an initial treatment for hearing loss that may reduce tinnitus (Turton et al., 2020). However, not all patient who are Deaf or have severe-profound hearing loss can use hearing aids (Wells et al., 2020).

The use of cochlear implants as a surgical intervention for severe-to-profound hearing loss has undergone significant changes in guidelines over the years (NICE, 2018). While there is some evidence of tinnitus improvement after cochlear implantation, there are currently no established guidelines specifically for addressing tinnitus using cochlear implants (Cima et al., 2019; Turton et al., 2020).

To address the psychological components of tinnitus disorder, CBT is highly recommended (Cima et al., 2019, NICE 2020). CBT encompasses various psychological interventions in the form of cognitive and behaviour therapies (Fuller et al., 2020). Behavioural therapy components include behavioural activation, exposure, and relaxation techniques. These techniques aim to assist individuals in overcoming learned connections between tinnitus (ringing in the ears) and unhelpful reactions, such as avoiding activities that worsen tinnitus.

By utilising these behavioural techniques, individuals can gradually reduce their avoidance behaviours and develop more adaptive coping strategies. Cognitive therapies target the link between thoughts and emotions. These therapies aim to identify and modify cognitive distortions related to experiences. For individuals with tinnitus, cognitive therapies may involve challenging negative thoughts and beliefs about tinnitus, reducing catastrophic thinking patterns, and promoting more positive and realistic thinking about their condition. By addressing these cognitive distortions, individuals can decrease distress and enhance their overall psychological well-being.

Several studies have demonstrated that CBT does not improve the loudness of tinnitus (Fuller et al., 2020; Grewal et al., 2014; Landry et al., 2020). However, the primary role of CBT is to reduce the impact of tinnitus on an individual's quality of life and address associated comorbidities like depression, anxiety, and insomnia. The Cochrane review of CBT for tinnitus included 28 studies (14 studies comparing CBT with no intervention or wait list control, three studies comparing CBT with audiological care, one study with TRT, and 16 studies comparing CBT with another active control in the form of relaxation, information, or internet-based discussion forum (Fuller et al., 2020). The studies included in the review only assessed the outcome of treatment immediately after, and the review concluded that the certainty of the superiority of CBT over other methods used in tinnitus management ranged from moderate to low.

According to Henry et al. (2022), audiologists can provide CBT to tinnitus patients in their audiology clinics. They argued that since many CBT treatments are self-administered and available online, audiologists can serve as the initial point of contact for patients seeking tinnitus treatmentClick or tap here to enter text.. However, it is crucial to be cautious when treating individuals with complex conditions, such as untreated mental health comorbidities or a history of significant mental illness or substance abuse.

Tinnitus retraining therapy (TRT) is a treatment approach based on Jastreboff's neurophysiological model (Jastreboff & Jastreboff, 2003). TRT is considered a habituation technique to reduce the impact of tinnitus on an individual's life. It involves manipulating the limbic, autonomic, and auditory system to reduce the response to abnormal stimulus. The goal of TRT is to achieve habituation and the weakening or disappearance of the functional connection between the auditory pathways and the limbic/autonomic nervous system. Hence, the patient still perceives tinnitus but is not bothered by it. Several studies have investigated TRT compared to other treatment modalities such as sound generators or CBT, typically finding them to be equivalent (Grewal et al., 2014). However, the European tinnitus guideline was not able to provide any recommendations regarding the effectiveness of this management option for tinnitus (Cima et al., 2019) due to insufficient research evidence.

The effectiveness of sound therapy, medication, and other treatments such as repetitive transcranial magnetic stimulation (rTMS) and transcranial direct current stimulation (tDCS) in managing tinnitus are supported by limited evidence, and therefore no recommendations were formulated in clinical guidelines. Sound therapy is a technique that uses generated sound to mask and provide a distraction from tinnitus. Sounds can be generated by devices specifically designed for this purpose or combined with hearing aids. In a Cochrane review conducted by Sereda et al. (2018), eight studies were analysed to compare the efficacy of sound therapy delivered through hearing aids versus sound generators or combination hearing aids. Most of these studies assessed tinnitus severity using tinnitus questionnaires, without considering secondary outcomes such as comorbidities or adverse effects. The findings did not provide sufficient evidence to support the use of sound therapy for tinnitus nor to favour one treatment over another (Sereda et al., 2018). Consequently, due to limited high-level evidence supporting its effectiveness, sound therapy has not been given a recommendation for or against in clinical practice guidelines for tinnitus (Cima et al. in 2019, NICE 2020).

Additionally, combination hearing aids may sometimes lead to increased tinnitus loudness in patients, particularly if not properly fitted or if the patient has conditions like hyperacusis (BSA, 2020).

Similarly, no medication appears to be an effective treatment for tinnitus (Cima et al., 2019; Elgoyhen & Langguth, 2010; Hall et al., 2011; S. H. Kim et al., 2021). Rather, there are recommendations against using drug therapy specifically for tinnitus. However, because tinnitus often has emotional and psychological effects, certain medications may be prescribed to address associated conditions such as depression, anxiety, mood disorders, insomnia, and concentration problems (Palumbo et al., 2015).

Repetitive Transcranial Magnetic Stimulation (rTMS) is a non-invasive technique used to modulate excitability in the motor cortex. It uses a wire coil to generate a magnetic field that is applied to the scalp (Klomjai et al., 2015). Its effectiveness for tinnitus management is uncertain due to the variability in study designs and a lack of reported safety measures, hence, there are recommendations against the use of rTMS in the treatment of tinnitus (Cima et al., 2019; Liang et al., 2020).

Transcranial Direct Current Stimulation (tDCS) involves the application of small electrical currents to the brain to stimulate nerve activity. There is no clinical guideline recommendation for its use due to insufficient research evidence (Cima, et al. 2019). In a recent systematic review by Labree et al. (2022) the impact of tDCS on tinnitus, depression, and anxiety, was examined. The review included 36 studies, of which 35 were parallel randomised controlled trials (RCTs) and one was a crossover RCT. Among these studies, six specifically investigated the use of tDCS for tinnitus management. The included studies demonstrated a significant effect, with active tDCS yielding better results than sham treatment. The mean difference on THI score in the included study was calculated to be -11.62 and statistically different in favour of the active condition (Labree et al., 2022).

Nevertheless, when considering the standard effect size, it was observed that these studies exhibited moderate heterogeneity in relation to tinnitus, while displaying high heterogeneity for anxiety and depression. It is worth noting that none of the studies provided information regarding the degree of hearing loss, therefore it is not clear whether this technique can be effective for tinnitus regardless of the severity of hearing loss.

In summary, most approaches to tinnitus management do not aim to cure tinnitus itself, but rather to alleviate its associated effects. Additionally, the effectiveness of these methods has typically only been assessed and reported for individuals with normal hearing or mild hearing loss, as opposed to those with severe impairment who may not wish to utilise hearing devices and solely seek relief for their tinnitus.

1.3. The lived experience of tinnitus

According to Larsen (2021) the lived experience of chronic illness includes the perception, beliefs, and behaviours of patients and their families, as well as the persons interpretation of the situation. This can manifest in feelings of loneliness, stigma, powerlessness, and more. Tinnitus, being a chronic condition, not only affects the individual but also has an impact on their immediate family members. In one of the earliest attempts to explore the subjective experience of tinnitus and gather valuable insights into its effects on individuals. Tyler & Baker, (1983) asked 72 participants in a tinnitus self-help group in Nottingham, UK, to provide their perceptions of tinnitus, the challenges they faced, and their priorities in managing the condition through open-ended questions. The problems reported by participants included lifestyle difficulties such as disruptions to sleep patterns, social life, work, and relationships. The second most reported issue was general health and healthcare, including reliance on medication for tinnitus, pain, headaches, and fatigue. Emotional problems such as depression and anxiety, and difficulty concentrating, was the third most common theme. Lastly, hearing issues such as difficulty understanding speech, television, and listening to

music, were reported. Notably, individuals who had experienced tinnitus for longer perceived it to be less of a problem compared to those with a shorter duration. The study also emphasised the importance of using open-ended questions to accurately capture the impact of tinnitus.

A retrospective analysis was conducted to explore the factors contributing to the perception of tinnitus as a problem (Watts et al., 2018). The analysis involved reviewing clinical data from patients who sought treatment at the Tinnitus and Hyperacusis Centre in London, UK. Through qualitative content analysis, responses from 678 patients were examined and categorised into 18 domains. The goal of the analysis was to gain insight into the experiences of tinnitus patients and identify specific problems they reported. The average age of patients included in the article was 57.2 years, with 64% of them being men (n=432). The most frequently reported problems related to reduced quality of life. Patients reported that tinnitus interfered with daily activities, impacted their work, disrupted their social life, and hindered relaxation. The second most frequently reported category of problem was the experience of fear, including fear of tinnitus itself or fear of its persistence in the future. Participants expressed a constant awareness of tinnitus, which consumed their attention.

Hall et al. (2023) replicated the study by Watts et al. (2018) in four major cities in China. The study included a question in the participants' main language, which asked why tinnitus is perceived as a problem. In addition to this open-ended question, closed questions were used to gather basic demographics and information about the characteristics of tinnitus. A total of 507 participants were recruited for the study, with 59% of them being women (297/507). The average age of the participants was 45.7 years. The study findings revealed that both the UK and China samples reported similar problems, although the prevalence rates varied between the two populations. Specifically, sleep disturbance and alertness were commonly reported issues in both groups, whereas it was not a very frequent concern for the UK population.

Interestingly, reduced quality of life was the most frequently reported problem in the UK, whereas the problem ‘feeling uncomfortable’ was derived from the Chinese sample. This term was used by Chinese participants to describe various situations that they found unpleasant.

Colagrosso et al. (2019) conducted a qualitative study using semi-structured interviews to examine the tinnitus experience in 27 participants in Canada who had varying degrees of hearing loss and had been experiencing chronic tinnitus for more than 6 months. The interviews revealed three main themes (Colagrosso et al., 2019). The first theme was the participants' appraisal of their tinnitus, where they provided detailed descriptions of the intensity, pitch, and duration of their tinnitus. This theme also included the participants' perception and reaction to their tinnitus. The second theme included factors that influenced the participants' tinnitus experience. These included environmental factors and individual factors such as attentional focus, stress levels, physical state, fatigue, and auditory effort. It was found that tinnitus was worse in silent environments or when wearing earplugs, while sound enrichment, such as listening to the radio, improved tinnitus. The third theme discussed the consequences of tinnitus on the participants' daily lives. While some participants denied any significant impact, others reported difficulties in living with tinnitus.

In a study conducted by Beukes et al. (2018) the perception of tinnitus as a negative experience was not universal. The researchers aimed to evaluate the feasibility and effectiveness of internet-based CBT as part of a clinical trial. The study involved 240 adults residing in the UK, who were asked to identify any positive experiences associated with tinnitus. Out of the participants, 78 individuals (32.5%) reported having at least one positive experience, while the remaining 162 reported no positive experiences. The positive experiences mentioned included coping, personal development, support, and outlook. The

study discovered that individuals who reported positive experiences tended to be younger, had less hearing impairment, and experienced fewer cognitive failures (Beukes et al., 2018).

Interviews were the preferred method for examining the impact of tinnitus and understanding the individual experiences within a community. These interviews can be conducted using open-ended or semi-structured questions. Different approaches, such as interpretive phenomenological (Marks et al., 2019) and narrative psychological (Erlandsson et al., 2020) approaches, and content analysis (Watts et al., 2018) have been employed in various studies to explore the tinnitus experience. Most studies examining the lived experience of tinnitus have been conducted in the UK or by UK-based researchers (Hall et al., 2023).

1.4. Gaps in the literature on tinnitus in adults who are D/deaf or have severe-to profound hearing loss

There is limited research on tinnitus in individuals who are deaf, whether they were born deaf or acquired hearing loss later in life, and those with severe and profound hearing loss. Several factors contribute to this gap. Firstly, severe and profound hearing losses are less common than mild-to moderate hearing losses. According to the World Health Organization (2021), there are approximately 1,153 million cases (14.9%) of mild hearing loss, compared to 30.7 million cases (0.4%) of severe hearing loss and 17.2 million cases (0.2%) of profound hearing loss globally. Secondly, individuals who became deaf before acquiring language skills often have limited vocabulary knowledge, leading to difficulties in reading comprehension (Alasim, 2021). Vocabulary knowledge encompasses two dimensions that are crucial for reading comprehension, namely breadth (the number of words known) and depth (the understanding of word meaning, orthography, and semantic relationships) (Nagy, 2005). As a result, deaf individuals often struggle with reading comprehension and face challenges in accessing healthcare information. For instance, during the COVID-19 pandemic, deaf

individuals relied more on social media platforms than official governmental websites for information (Almusawi et al., 2021).

Thirdly, individuals with deafness or severe-profound hearing loss often have lower levels of health knowledge, resulting in decreased personal health literacy. Health literacy refers to the ability of individuals to find, understand, and utilise information and services to make informed decisions and take appropriate actions regarding their health and the health of others (Santana et al., 2021). Wells (2020) conducted a study in older adults to investigate the relationship between health literacy and hearing loss. The study involved 12,223 individuals aged 65 and over who completed a self-report health literacy assessment. The assessment categorised health literacy as either limited or adequate based on the question; how confident are you filling out medical form by yourself? (Wells et al., 2020). They found a positive correlation between severe hearing loss and limited health literacy.

A fourth factor was that due to low health literacy and communication difficulties, D/deaf patients encounter various barriers when seeking healthcare advice, leading to frustration and mistrust of healthcare providers (Barnett, 2002). Conversely, healthcare professionals who are unaware of the communication needs of Deaf patients may inadvertently use written language instead of sign language (Velonaki et al., 2015). In a study assessing nurses' knowledge, attitudes, and behaviour towards Deaf patients, 200 randomly selected nurses completed a questionnaire to evaluate their knowledge (Velonaki et al., 2015). Based on the research findings, it was discovered that 55% of nurses reported a limited or inadequate understanding of Deaf patients, while 89% lacked knowledge in sign language communication. The research findings emphasised the importance of implementing educational programs that involve interactions with Deaf individuals. These programs can greatly enhance nurses' knowledge and attitudes towards Deaf people.

One further factor contributing to gaps in the literature on tinnitus in deafness is that some researchers suggest that tinnitus development requires damage to any part of the auditory pathway, and prior auditory experience is important for its occurrence (Eggermont & Kral, 2016). As a result, they suggested that individuals who were deaf since birth or early in life were less likely to experience tinnitus. This is supported by a study that found that congenitally deaf individuals report tinnitus less frequently than those who acquired deafness later in life (Knipper et al., 2020). For example, individuals with a Connexin26 mutation (GJB2 gene) who have been deaf since birth have a significantly lower prevalence of tinnitus or near absent tinnitus experience (Tsukada et al., 2010).

The inclusion of individuals with deafness or severe-profound hearing loss in tinnitus studies is often hindered by communication challenges and the reliance on interpreters to bridge the gap in understanding. For example, a study by Zarenoe & Ledin (2013) aiming to investigate the tinnitus burden experienced by hearing impaired people excluded participants who required an interpreter (those who have hearing loss greater than 70 dB HL) because it was financially inaccessible during the study. As such, there is real need for studies to be fully resourced to include and avoid bias against adults who are deaf or have severe to profound hearing loss so that their lived experience of tinnitus is reported.

1.5. Study aims and objectives

The aim of this PhD was to understand the lived experience of tinnitus in D/deaf and severe-profoundly hearing-impaired adults in two distinctive study samples, Saudi Arabia and United Kingdom.

The objectives were to:

1. Catalogue the existing literature on the experience of tinnitus in deaf and severe-to-profoundly hearing-impaired adults through a scoping review (Chapter 2).

2. To investigate tinnitus experience in SA and UK through mixed method approaches using the validated Tinnitus Handicap Inventory (Arabic and English) and further explore the phenomena using semi-structured interviews (Chapters 4 and 5).
3. To identify commonly reported problems among the study samples and map these problems to available tinnitus questionnaires (Chapter 6).

Chapter 2 A Scoping review to analyse what exists in the literature regarding tinnitus management in deaf and severe-profound hearing-impaired adults.

2.1 Introduction

Chapter 1 reviewed the current understanding and guidelines for managing tinnitus clinically, including both recommended and non-recommended treatments. However, there is no specific approach tailored to the needs of deaf and severely hearing-impaired adults when it comes to implementing these management strategies. Therefore, it is important to catalogue the existing literature to fill this knowledge gap.

A scoping review is a structured process that differs from a systematic review. While a systematic review is used to gather evidence for a specific question (Charrois, 2015), a scoping review has a broader purpose. It is particularly useful when the literature has not been comprehensively reviewed or when it is complex and diverse, making it difficult to conduct a more precise systematic review (Munn et al., 2018; Peters et al., 2015, 2020).

Munn (2018) suggested that a scoping review is useful in several scenarios. Firstly, it can help identify and analyse knowledge gaps. Additionally, it can be employed to ascertain the types of evidence that exist in a specific field. Furthermore, it can be utilised to examine research practices in a particular topic or field. Lastly, it can serve as a preliminary step before conducting a systematic review.

2.1.1 Aim and objectives

The aim of conducting this scoping review was to provide a comprehensive overview of the existing evidence on the current state of research in the field of assessment and treatment of tinnitus in individuals who are deaf or have severe-profound hearing loss.

2.2 Methods

This scoping review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-analysis extension for scoping reviews (PRISMA-ScR, Tricco et al., 2018).

2.2.1 Eligibility criteria

Records were included if they reported baseline information on the impact of subjective (primary) tinnitus in adults who were identified as deaf or having severe-to-profound hearing loss. The inclusion criteria were based on the population, concept, context (PCC) mnemonic (Table 2.1).

Target population: adults aged 18 years old or older, bilateral deafness prelingually or with severe-to-profound post lingual hearing loss who also report tinnitus.

Concept: Experience and management of chronic subjective tinnitus (lasting more than 6 months) in deafness. Expected management strategies include, but are not limited to, education, counselling, and sound-based therapies such as hearing aids or cochlear implants.

Context: no restrictions regarding time or geography.

Studies were excluded if they only included adults with normal hearing or mild-to-moderate hearing loss without reference to severe-to-profound hearing loss. Additionally, studies focusing on objective (secondary) tinnitus, studies involving only children, and those not available in English were excluded. Sudden hearing loss, which can be associated with acute tinnitus, as well as unilateral hearing loss, were also criteria for exclusion.

Table 2.1 Inclusion and exclusion criteria

Criteria for Inclusion	Criteria for exclusion
➢ Adults aged 18 years and older. ➢ Bilateral severe/profound hearing loss and deafness ➢ Subjective tinnitus ➢ Published in English language	➢ Children ➢ Adults with normal and mild-moderate hearing loss ➢ Objective tinnitus ➢ Sudden or unilateral hearing loss

2.2.2 Information sources

To identify potentially relevant documents, the following databases were searched in July 2020: MEDLINE, EMBASE, PsycInfo, Web of science, CINAHL, ProQuest, Scopus, Ethos, PubMed, and Google Scholar.

2.2.3 Search strategy

Tinnitus was used as the MESH where “deaf” and “profound hearing impair*” were searched as keywords. An example search strategy for MEDLINE can be seen in Table 2.2

Table 2.2 An example of search strategy used for MEDLINE via OVID SP

1	Tinnitus
2	(deaf or profound hearing impair*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]
3	1 and 2

2.2.4 Selection of source of evidence

To increase consistency among reviewers, all reviewers screened the same exported records from each database. The records were screened independently at two levels. Level 1 evaluated the titles and abstracts, and if reviewers agreed, the records passed to level 2 which involved screening the full text.

2.2.5 Data charting process

Data were charted according to the aims of the scoping review. Major themes that emerged were tinnitus impact pre-intervention, intervention, and tinnitus impact post intervention.

2.2.6 Data items

Data were extracted based on record characteristics such as publication year, study design and country of origin, population description including description of hearing loss, aetiology of hearing loss and then impact of tinnitus (comorbidity and its assessment tools, tinnitus questionnaires and any other instrument used to assess tinnitus) and finally intervention type

and difference between them pre and post intervention and any other relevant findings and recommendations.

2.3 Results

Searches returned 9,186 records of which 6,044 duplicates were removed. Hence, the abstract and title of 3,142 records were screened for potential inclusion. The result was 63 records eligible for full text screening. After full text screening 36 records were included (Figure 2.1). Reviewers only disagreed on one record for inclusion/exclusion, and in this case the record was discussed with a third reviewer leading to a majority decision to include the record.

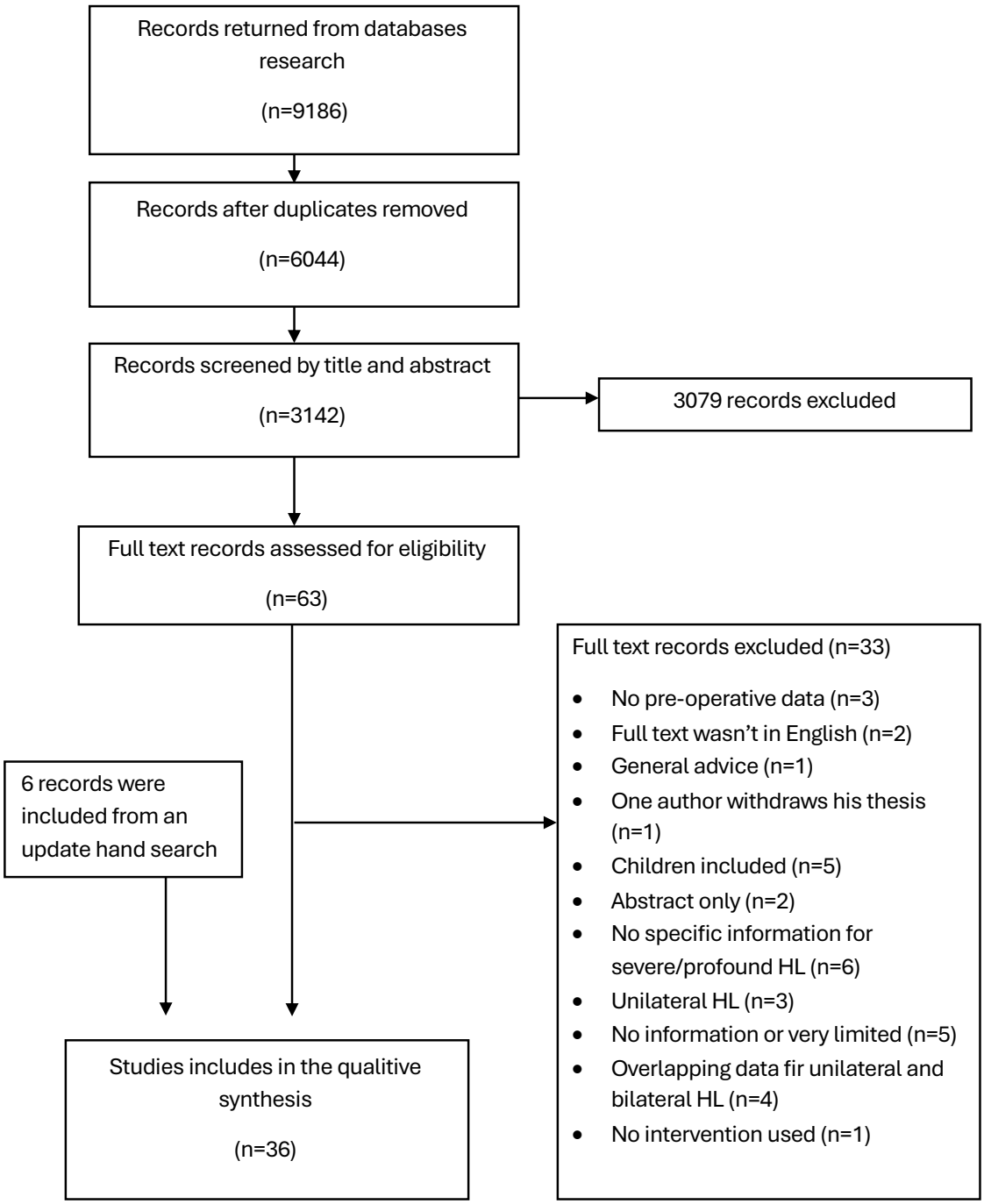


Figure 2.1 Flowchart showing the process of extracting, screening and analysing data

2.3.1 Study demographic

Of the 36 included records (Table 2.3), 14 were prospective case studies (observational research method that follows individuals over time collecting data to examine potential causal relationships with controlled variables and predetermined outcomes), 11 were retrospective

case reviews (research method that examines past events using existing data), three were case reports (detailed descriptions of individual patient cases, often used to report unique or rare findings), two were cross-sectional studies (research method that examines a population at a specific point in time to measure the prevalence of outcomes), two were part of RCTs (experimental studies where participants are randomly assigned to different groups to compare interventions), one was a narrative (focuses on collecting and analysing stories or accounts of experiences), one was a case study (involves in-depth, detailed examinations of particular cases within real-world contexts), one was a non-randomized controlled clinical trial (similar to RCTs but without random assignment of participants to groups), and one was a combined retrospective and prospective study (incorporates both past data analysis and future follow-up, combining elements of retrospective and prospective approaches).The earliest record was published in 1988 and the most recent was published in 2021 (Figure 2.2). Most studies were published in the last decade. Records originated from 15 countries with most originating from the USA (Figure 2.3).

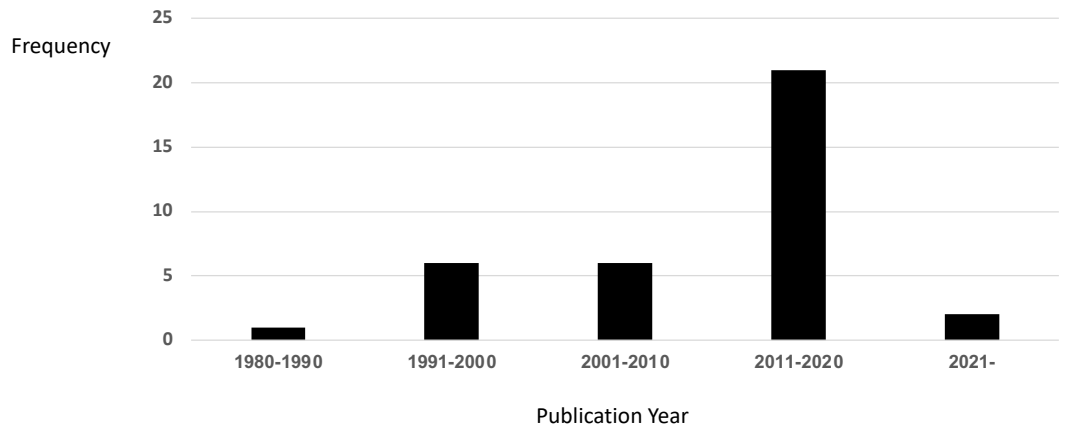


Figure 2.2 Distribution of included studies by year

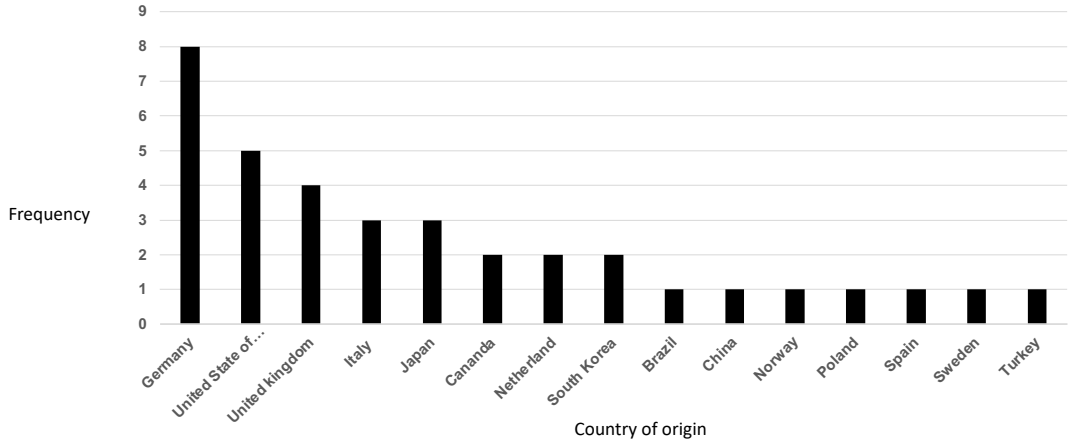


Figure 2.3 Distribution of included studies by year

The characteristics of included studies are summarised in Table 2.3.

Table 2.3 The characteristic of included studies

	YEAR	FIRST AUTHOR	TITLE	COUNTRY	STUDY DESIGN	STUDY POPULATION	TOTAL SAMPLE (WITH TINNITUS)	AGE
1	1988	Per Lindberg	Effects of self-control training on tinnitus in a deaf patient: A case study	Sweden	Case study.	Post-lingually deafened	1 (1)	26
2	1992	Charles R. Souliere	Tinnitus suppression following cochlear implantation. A multifactorial investigation	USA	Retrospective cohort study.	Cochlear implant users (sever-profound SNHL)	33 (28)	21-74
3	1994	Juichi Ito (a)	Tinnitus suppression by electrical stimulation of the cochlear wall and by cochlear implantation"	Japan	Retrospective case study	Cochlear implant users with pre implant tinnitus (sever-profound SNHL)	30 (26)	18-63
4	1994	Juichi Ito (b)	Suppression of tinnitus by cochlear implantation	Japan	Retrospective case study.	Cochlear implant users with pre implant tinnitus (sever-profound SNHL)	20 (18)	8-61
5	1995	Richard S. Tyler	Tinnitus in the profoundly hearing-impaired and the effects of cochlear implants"	USA	Retrospective cohort study	Profoundly deaf cochlear implant users	82 (22)	34-68
6	1997	Richard T. Miyamoto	Electrical suppression of tinnitus via cochlear implants"	USA	Retrospective cohort study.	Cochlear implant users (sever-profound SNHL)	64 (49)	

7	1998	Yotaka. Fukuda	The AllHear cochlear implant and tinnitus	Brazil	Case report	Cochlear implant users with pre-implant tinnitus (sever-profound SNHL)	6 (6)	17-64
8	2001	Michael J. Ruckenstein,	Tinnitus suppression in patients with cochlear implants	USA	Prospective cohort Study	Cochlear implant candidates who complain of pre implant tinnitus (sever-profound SNHL)	38 (38)	>18
9	2007	Walter Di Nardo	Tinnitus modifications after cochlear implantation	Italy	Retrospective case studies	Cochlear implant users (Sever-profound SNHL)	30 (20)	16-74
10	2008	Nicola Quaranta	The effect of unilateral multichannel cochlear implant on bilaterally perceived tinnitus	Italy	Prospective cohort study	Cochlear implant users who complain of pre implant tinnitus (sever-profound SNHL)	62 (41)	17-77
11	2009	Tao Pan	Change in the Tinnitus Handicap Questionnaire After Cochlear Implantation	Canada	Retrospective cohort study	Cochlear implant users who complain of pre implant tinnitus (sever-profound SNHL)	244 (153)	18-90
12	2009	Walter Di Nardo	Transtympanic electrical stimulation for immediate and long-term tinnitus suppression"	Italy	Prospective cohort study	post lingual monaural or binaural profound hearing loss and with	11 (11)	34-64

						severe and disabling tinnitus in the worse ear		
13	2010	Elisabeth Masgoret Palau	Tinnitus and cochlear implantation. Preliminary experience	Spain	Retrospective cohort study/ Case Reports	Cochlear implant users who complain of pre implant disabling tinnitus (sever-profound SNHL)	3 (3)	32-57
14	2011	Heidi Olze	Cochlear Implantation Has a Positive Influence on Quality of Life, Tinnitus, and Psychological Comorbidity	Germany	Prospective cohort study	Cochlear implant users with pre-implant tinnitus (sever-profound SNHL)	43 (39)	19-77
15	2012	Heidi Olze (a)	Elderly patients benefit from cochlear implantation regarding auditory rehabilitation, quality of life, tinnitus, and stress"	Germany	prospective cohort study	Cochlear implant users (sever-profound SNHL)	55 (20) older 55 (35) younger	17-67
16	2012	Heidi Olze (b)	Extra benefit of a second cochlear implant with respect to health-related quality of life and tinnitus"	Germany	prospective cohort study	Cochlear implant users (sever-profound SNHL)	40 (28)	Not reported
17	2012	Heidi Olze (c)	The impact of cochlear implantation on tinnitus, stress and quality of life in postlingually deafened patients	Germany	prospective cohort study	Cochlear implant users who complain of pre implant tinnitus (sever-profound SNHL)	32 (28)	19-77
18	2013	Dong-Kee Kim	Tinnitus in patients with profound hearing loss and the effect of cochlear implantation"	South Korea	Retrospective cohort study	Cochlear implant users (sever-profound SNHL)	35 (22)	47.5+_15.1

19	2015	David Greenberg	Developing an assessment approach for perceptual changes to tinnitus sound characteristics for adult cochlear implant recipients	United Kingdom	Prospective cohort study	Cochlear implant users with pre implant tinnitus (sever-profound SNHL)	68 (64)	31-68
20	2015	Ingo Todt	Relationship between intracochlear electrode position and tinnitus in cochlear implantees	Germany	Retrospective cohort study	Cochlear implant users with pre implant tinnitus (sever-profound SNHL)	55 (36)	Not reported
21	2015	Sarah M. Theodoroff	Experimental Use of Transcranial Magnetic Stimulation (TMS) to Treat Tinnitus in a Deaf Patient	United states of America	Case study	Pre lingual deaf	1 (1)	26
22	2015	Sarah L. Wheeler	Tinnitus: A Deafhearing Phenomenon	United Kingdom	Narrative	Pre lingual deaf (Waardenburg)	1 (1)	Not reported
23	2016	Alice van Zon	Effect of unilateral and simultaneous bilateral cochlear implantation on tinnitus: A Prospective Study	Netherland	"prospective cochort study (part of randomised controlled trails)	Cochlear implant users with pre-operative tinnitus (sever-profound SNHL)	38 (16)	Not reported
24	2016	Dong-Kee Kim	Prospective, Multicenter Study on Tinnitus Changes after Cochlear Implantation	Republic of Korea	Prospective cohort study	Bilateral deaf cochlear implant candidates (sever-profound SNHL)	79 (59)	51.5±14.7
25	2016	Robert H. Pierzycki	Tinnitus and Sleep Difficulties After Cochlear Implantation	United Kingdom	A population-based cohort, prospective	Cochlear implant candidates	211 (113)	40-69

						Who complain of tinnitus and didn't receive implant (sever-profound SNHL)		
26	2016	Steffen Knopke	Impact of cochlear implantation on quality of life and mental comorbidity in patients aged 80 years	Germany	prospective cohort study	Cochlear implant candidates (sever-profound SNHL)	17 (12)	< 80
27	2016	Ying Liu	Suppression of Tinnitus in Chinesen Patients Receiving Regular Cochlear Implant Programming	China	Prospective study, randomised controlled.	Cochlear implant candidates who complain of pre implant tinnitus (sever-profound SNHL)	234 (108)	>18
28	2017	Piotr H. Skarzynski	Tinnitus severity in patients with cochlear implants	Poland	intervential (experimental) clinical trials"	Bilateral cochlear implant users who complain of pre-operative tinnitus (sever-profound SNHL)	46 (46)	18-85
29	2017	Steffen Knopke	Cochlear implantation of bilaterally d eafened patients with tinnitus induces sustained decrease of tinnitus-related distress	Germany	prospective, longitudinal analyses	Bilateral cochlear implant with pre implant tinnitus (sever-profound SNHL)	41 (41)	25-81
30	2018	Geerte G J Ramakers	Development and internal validation of a multivariable prediction model for tinnitus recovery following	Netherland	Retrospective cross-sectional study	Bilateral deaf cochlear implant users with pre implant tinnitus (sever-profound SNHL)	137 (87) Recovered n=35 Non recovered n=52	58.3-71.2

			unilateral cochlear implantation: a cross-sectional retrospective study					51.7-66.2
31	2018	Saeko Matsuzaki	Severe tinnitus in a patient with acquired deafness for over 50 years: A case report	Japan	Case report	Deaf lady	1 (1)	68
32	2020	Manuel Christoph Ketterer	Binaural Hearing Rehabilitation Improves Speech Perception, Quality of Life, Tinnitus Distress, and Psychological Comorbidities"	Germany	Prospective cohort study	Cochlear implant users (sever-profound SNHL)	53 (29)	28-80
33	2020	Peter R. Dixon	Predicting Reduced Tinnitus Burden After Cochlear Implantation in Adults	Canada	Retrospective cohort study	Cochlear implant users with pre-operative tinnitus (sever-profound SNHL)	358 (358)	>_18
34	2020	Elif Tugba Sarac	Effects of Cochlear Implantation on Tinnitus and Depression	Turkey	Retrospective cohort study.	Cochlear implant users who complain of pre implant tinnitus (sever-profound SNHL)	23 (23)	20-67
35	2021	Robert H. Pierzycki	Insomnia, Anxiety and Depression in Adult Cochlear Implant Users With Tinnitus	United Kingdom	Cross sectional	Cochlear implant users with pre-operative tinnitus (sever-profound SNHL)	127(67)	Average age was (53.93) 18.98%

2.3.2 Study Population

Most records focused on post-lingually deaf cochlear implant users or candidates who reported tinnitus before implantation. Causes of hearing loss, where mentioned, included infections such as meningitis, or head trauma, and were described in some as either sudden or progressive. Five records reported on prelingually deaf adults.

2.3.3 Theme 1: Impact of tinnitus in the D/deaf and adults with severe-to-profound hearing loss

Table 2.4 summarises the assessment tools and evaluation of impact of tinnitus pre- and post-intervention, changes in tinnitus attributed to interventions and assessed comorbidities in D/deaf adults and severe-profound hearing-impaired adults.

Table 2.4 Intervention used to assess and treat tinnitus

RE	YEAR	FIRST AUTHOR	TOOLS USED TO ASSESS TINNITUS	TINNITUS IMPACT PRE-INTERVENTION	INTERVENTION	TINNITUS IMPACT POST INTERVENTION	COMORBIDITIES ASSESSED
1	1988	Per Lindberg	Visual analogue scale (VAS) for (STL) and (DT) and (TC)	Right sided tinnitus (high pitched) and changes all over the days and associated with headache and muscle pain	Behavioural approach	Reduced STL and DT and increase TC over time. She felt self-control and her associated symptoms improved.	None
2	1992	Charles R. Souliere	Closed set of questionnaires assessing tinnitus loudness, location, and residual inhibition	Pre-operative loudness (6.5±2.2) annoyance (5.6±2.8)	Unilateral cochlear implant	1. Loudness: 15 (54%) reported a tinnitus loudness decrease, 12 patients (43%) reported no change, and one patient (3%) noted an increase in loudness. 2. Annoyance: postoperative annoyance (3.4±2.9, 1=3.12, P<.002) 12 patients (43%) noted a decrease in annoyance, 14 noted no change, and two (7%) noted an increase in annoyance.	None
3	1994	Juichi Ito	Tinnitus loudness was assessed as either (marked, slight or none)	Tinnitus loudness was marked in 8 cases (27%) and slight in 18 cases (13%).	Unilateral cochlear implant	Tinnitus disappeared: 6 cases (23%) suppressed: 12 cases (46%) no change 8 cases (31%) aggravated 0 (0%) so tinnitus was abolished in 69%	None

4	1994	Juichi Ito	The degree of tinnitus is classified to marked, slight and none at time of promontory stimulation and after cochlear implant surgery.	Prior to cochlear implant surgery, five patients (25%) had marked tinnitus and 13 patients (65%) had slight tinnitus.	Unilateral cochlear implant	At time of promontory stimulation: 4 cases (22%) disappeared, and 9 cases (50%) suppressed and 5 cases (28%) no change to their tinnitus. The degree of tinnitus changed after cochlear implant: 8 cases disappeared (44%), 7 cases suppressed (39%), no change in 2 cases (11%) and aggravated in one case (6%) so it was disappeared or suppressed in 83 %	None
5	1995	Richard S. Tyler	THQ	Bothersome tinnitus and THQ overall score averaged 33.2% (SD=24.7; range 8-84)	Unilateral cochlear implant	Mean total THQ was 31.2%	Depression
6	1997	Richard T. Miyamoto	THI	Not reported	Unilateral cochlear implant	Mean THI post implant was 20.05	None
7	1998	Yokata. Fukuda	Not applicable	6 cases: 1. Bilateral, high-frequency tinnitus of moderate intensity. 2. High frequency disabling tinnitus in the head 3. A hissing-type bilateral tinnitus of mild in- tensity 4. High-pitched tinnitus of mild intensity 5. Bilateral ringing tinnitus of	Unilateral cochlear implant	1. Tinnitus was relieved bilaterally. When the external unit is turned off, he has a residual inhibition of tinnitus for 10 minutes. 2. Tinnitus was relieved partially, with no residual inhibition. 3. Tinnitus disappeared on both sides when the cochlear implant was turned on. She had residual inhibition of her tinnitus for 30 minutes. 4. Tinnitus was unchanged with the cochlear	None

				moderate intensity. 6. She had no tinnitus before surgery.		device. 5. Tinnitus disappeared in the ear in which the device was implanted. 6. Shock, pain, and tinnitus as soon as the electrical device was turned on.	
8	2001	Michael J. Ruckenstein	A semiquantitative scale before and after cochlear implantation. Tinnitus is categorized based on its severity using a numeric scale	21 patients (55%) had marked tinnitus, described as severe or debilitating (level 4 or 5) scale 5: 15 cases (39.4%) scale 4: 6 cases (15%) scale 3: 13 cases (34.2%) scale 2: 4 cases (10.5%) scale 1: 0 cases	Unilateral cochlear implant	17 patients (45%) had a complete suppression of their tinnitus. Nine- teen patients (50%) had some suppression of tinnitus, and only three patients (5%) noted no change in their tinnitus levels. Thus, 35 of 38 patients (92%) noted a reduction in their tinnitus levels after implantation. No patient suffered an exacerbation of his or her tinnitus after implantation. Scale 5: 1 case (2.6%) scale 4: no Scale 3: 5 cases (13.15%) Scale 2: 15 cases (39%) Scale 1: 17 cases (44.7)	None
9	2007	Walter Di Nardo	THI, tinnitus loudness, type of sound and its duration and severity.	Overall, THI scores were 44.5	Unilateral cochlear implant	Overall, THI scores were 22.75	Sleeping difficulties

10	2008	Nicola Quaranta	THI	The average THI score before cochlear implantation was 32 (standard deviation (SD) 24)	Unilateral cochlear implant	The average THI score after cochlear implantation was 12 (SD 20)	None
11	2009	Tao Pan	THQ	THQ pre implant total score is 41.2, SD 22.35	Unilateral cochlear implant	THQ post implant total score is 29.8, SD 19.45	None
12	2009	Walter Di Nardo	THI and tinnitus pitch, loudness. Also, minimum masking level (MML) on the day of the EPS session	Total THI pre-EPS 49	Electrical promontory stimulation (EPS)	THI one month after EPS 33	None
13	2010	Elisabeth Masgoret Palau	THI	Case one THI was not measured. Case 2 THI = 94 Case 3 THI = 46	Unilateral cochlear implant	Case 2: THI = 70 at 6 months. Case 3 THI =10 at 6 months	Hyperacusis, and hypoacusis
14	2011	Heidi Olze	TQ	TQ scores were 30.9 -+ 18.8	Unilateral cochlear implant	TQ decreased to 23.6 6 15.8 after CI (P < .01)	Depression, stress & anxiety
15	2012	Heidi Olze (a)	TQ	TQ score of the older patients was 26.3 ± 23.1 where in younger patients TQ score before implantation was ± 29.1	Unilateral cochlear implant	TQ scores in elderly was 22.3 ± 17.7 While in younger group decreased 21.0 ± 15.3	Stress
16	2012	Heidi Olze (b)	TQ	Initial TQ score was 32.6 ± 21.2.	Bilateral cochlear implant/ sequential within 6 months	TQ score decreased to 12.8 ± 12.5	Not assessed

17	2012	Heidi Olze (c)	TQ	TQ mean total score was 33.4	Unilateral cochlear implant	TQ mean total score was 20.3	Stress
18	2013	Dong-Kee Kim	THI	THI mean scores were 50.5±28.7	Unilateral cochlear implant	THI mean scores were 10.1±15.8	None
19	2015	David Greenberg	THI	Mean THI pre was 42 (moderate handicap)	Unilateral cochlear implant	Mean THI at 12 months was 22	None
20	2015	Ingo Todt	mini TQ12	Group 1: mean TQ12 6.9 Group 2: mean TQ12 3.8 Group 3: mean TQ12 4.8 Group 4: mean TQ12 6.7	Unilateral cochlear implant	Group 1: mean TQ12 6.3 Group 2: mean TQ12 2.5 Group 3: mean TQ12 5.4 Group 4: mean TQ12 9	None
21	2015	Sarah M. Theodoroff	TFI as a primary outcome measure and THI	TFI score 27.6 THI score 18	Repetitive Trans-cranial magnetic stimulation (rTMS)	TFI post TMS 44 and follow up after 26 weeks was 25.2 THI post TMS 18 and follow up after 26 weeks 14	Depression, Anxiety
22	2015	Sarah L. Wheeler	None	"Sometimes it's like a bomb—boom! Then my eyes swirl round as if I have spun round the room but I haven't and it has happened in a split second. Then a long wheeee whistle, winding down. then to a ringing ring, noise. I prefer the boom type because it slows down the tinnitus rather than the ringing one which goes on forever."	No intervention/ proposed coping strategies	His brain got used to it.	None

23	2016	Alice van Zon	THI and TQ	Overall median THI score in unilateral pre op was 8 (2-32) where in bilateral it was 22 (0-48) Overall TQ score in unilateral 7 (0-33) while in was 20 (1-41) in bilateral CI	Unilateral and bilateral cochlear implant	Overall median THI score in unilateral post implant was 2 (0-6) where in bilateral it was 12 (0-28) Overall TQ score in unilateral 7 (0-21) while in was 9 (0-26) in bilateral CI	None
24	2016	Dong-Kee Kim	THI Korean version	THI mean total score pre implant was 45.5±26.8	Unilateral cochlear implant	THI mean total scores immediately after implant was 40 and after 6 months 23	Depression & stress
25	2016	Robert H. Pierzycki	Self-reported measures of hearing, tinnitus type, and sleep difficulty in cochlear implant candidates in	Not reported	Unilateral cochlear implant	Not reported	Sleeping difficulties
26	2016	Steffen Knopke	TQ	The mean value of TQ score before implantation was 18.5 ± 23.0	Unilateral cochlear implant	The mean value of TQ score post implantation was 13.2 ± 15.9	Depression Stress Anxiety
27	2016	Ying Liu	THI	Pre implant, mean THI control group 84 where mean THI programming group 80	Unilateral cochlear implant	**At 6 weeks:** Programming 65 Control 70 **At 8 weeks:** Programming,50 Control 64.5	None

						At 12 weeks: Programming 50 Control group 60	
28	2017	Piotr H. Skarzynski	THI &TFI	Mean pre-operative THI score of the tinnitus group was 39.9 Mean TFI 38.4	Unilateral cochlear implant	mean THI score pre-operative of the tinnitus was 25.6. mean TFI 29.2	None
29	2017	Steffen Knopke	TQ	Mean TQ score 35	Unilateral cochlear implant	Mean TQ score 27.54	None
30	2018	Geerte G J Ramakers	Self-developed questionnaires assessing tinnitus severity (mild/moderate/severe)	Not reported	Unilateral cochlear implant	Tinnitus recovery was evident in 40% while worsening of tinnitus following cochlear implant was 10% in years.	Anxiety Depression
31	2018	Saeko Matsuzaki	THI	THI score was at first visit 94	Medication (Antidepressant, sleep induction). Psychotherapy	THI score at 4.5 years was 0	Depression, anxiety
32	2020	Manuel Christoph Ketterer	TQ	Mean pre-operative TQ was 25.2	Bilateral sequential CI	Mean TQ post-operative in 24 months was 15.1	Anxiety Depression & stress
33	2020	Peter R. Dixon	THI	Mean THI score was 22 (0-50)	Unilateral cochlear implant	THI reduction by at least 7-points was observed in 262 (73.2%) patients, of whom 155 (59.2%) reported complete resolution.	None

34	2020	Elif Tugba Sarac	THI Turkish version	THI mean SCORE was 61±26.2	Unilateral cochlear implant	THI mean SCORE was 36.9±29.2	Depression
35	2021	Robert H. Pierzycki	THI	Mean THI in tinnitus group was 21.14	Unilateral cochlear implant	Not reported	Anxiety Depression Insomnia
36	2021	Arne K. Rødvik	THI	Mean THI score pre-implantation was 61.3	Bilateral sequential cochlear implant	Mean THI score post-second implantation was 20.3 (SD16.3)	None

THI: Tinnitus Handicap Inventory; TQ: Tinnitus Questionnaire; THQ: Tinnitus Handicap Questionnaire; TFI: Tinnitus Functional Index; mini TQ12: mini–Tinnitus Questionnaire 12,;VAS: Visual Analog Scale; STL: Subjective Tinnitus Loudness; DT: discomfort from tinnitus: TC: ability to control tinnitus; SQ: Perceived Stress Questionnaire; BDI-II: Depression Inventory II;BDI: Beck's Depression Index; STAI: State Trait Anxiety Inventory; GAD-7: Generalized Anxiety Disorder; HRQoL: Health related quality of life; MML: Minimum Masking Level; SD: standard deviation

Tinnitus assessment tools reported in the literature included validated tinnitus questionnaires (n=26), non-validated tinnitus questionnaires (n=4), visual analogue scales of tinnitus loudness or annoyance (n=6), and minimum masking levels (n=2). The validated tinnitus questionnaires used comprised: THI (Newman et al., 1996) (n=17), TQ (Hallam, 2009) (n=7), TFI (Kuk et al., 1990; Meikle et al., 2012) (n=2), Tinnitus Handicap Questionnaire; THQ (Kuk et al., 1990) (n=2), and the mini-Tinnitus Questionnaires 12; miniTQ12 (Hiller & Goebel, 2004) (n=1). No problems with the administration of these questionnaires were reported and several had been translated into additional languages from the original. There were three studies which used non-validated questionnaires containing questions about tinnitus duration, loudness, severity, and related comorbidities.

The THI was used to assess tinnitus severity before cochlear implantation in 17 studies and once in a case study involving a deaf female receiving antidepressant treatment. Although the TFI was used as a primary outcome measure to evaluate treatment including TMS and in unilateral cochlear implantation, it was used in conjunction with the THI.

Records commonly reported tinnitus experience either as a testimony from patients or in the format of the patient rating their tinnitus either using validated questionnaires or other assessment tools. For example, Ruckenstein et al. (2001) assessed tinnitus severity using an ordinal scale from 1= no tinnitus to 5= debilitating tinnitus. Some records recounted the individual experience: *"Sometimes it's like a bomb—boom! Then my eyes swirl round as if I have spun round the room, but I haven't, and it has happened in a split second. Then a long wheeee whistle, winding down. then to a ringing ring, noise."* This statement was from an adult who had been deaf since birth describing his tinnitus attacks (Wheeler & Hopwood 2015). He further stated that he preferred one type of tinnitus characteristic over others because of the duration *"I prefer the boom type because it slows down the tinnitus rather than the ringing one which goes on forever".* Another statement from a 26-year-old deaf

female with a hearing impairment attributed to an acoustic neuroma and right sided tinnitus (Lindberg, 1998) described her tinnitus as high pitched and a screaming sound that could go to an unbearable level several times a day. In general tinnitus characteristics such as type of sound, tinnitus duration, and localisation were reported (Di Nardo et al., 2007; Greenberg et al., 2015).

2.3.4 Theme 2: Primary treatment of tinnitus in D/deaf adults

Included studies are described here according to whether the intervention was used primarily to treat tinnitus or to treat other conditions. There were only four studies where the intervention was given primarily to treat tinnitus, and one conversation piece on coping strategies proposed by a deaf patient. The latter was a case study of a 26-year-old female with deafness following removal of an acoustic neuroma, reporting the use of a behavioural treatment approach aiming to relieve tinnitus over 5 consecutive months with self-control muscular relaxation techniques. The result was an improvement following therapy whereby the patient reported that she felt in control of her condition (Lindberg, 1998).

Repetitive transcranial magnetic stimulation (rTMS) to treat tinnitus was used in one study reporting the effects in a 28-year-old post-lingually deaf (hearing impairment occurred at 5 years of age) female with tinnitus. The treatment consisted of 10 sessions of rTMS using 2,000 pulses per session at a stimulation rate of 1 Hz via a coil that was in an adjustable stand against the left side of her head (Theodoroff & Folmer, 2015). Her tinnitus did not improve as a result of the treatment as assessed with TFI and THI questionnaires.

A 69-year-old Deaf (hearing impairment occurred before 5 years of age) female complained of severe tinnitus, as well as depression and anxiety since tinnitus onset (Matsuzaki et al., 2018). In this case, oral antidepressants (the selective serotonin reuptake inhibitor paroxetine hydrochloride, Paxil®, 12.5 mg, starting at one tablet a day and increasing to three tablets a

day) were given. She additionally received night sedation (suvorexant, Belsomra®, 15 mg, one tablet a day). Her tinnitus was intermittent and subsided completely after 4 and a half years.

One record investigated tinnitus suppression following electrical promontory trans-tympanic stimulation in 11 patients with monaural or binaural profound hearing loss (Di Nardo et al., 2009). Stimulations were given at various frequencies (50, 100, 200, 400, 800, and 1600 Hz) at ascending levels to find the participant's threshold for at least 60 seconds and then the discomfort level in μA. Nine out of 11 patients (81.8%) had immediate suppression of their tinnitus following electrical promontory trans-tympanic stimulation with no worsening of tinnitus reported. The most effective stimulation frequencies were 50 and 100 Hz. However, data were pooled so the effects specific to bilateral hearing loss could not be extracted.

One study reported a conversation between two relatives. Both presented with Waardenburg Syndrome, one being Deaf since birth and the other exhibiting an unspecified hearing loss (Wheeler & Hopwood, 2015). They complained of different attacks of tinnitus with different descriptors such as bomb, whistle, and ringing. However, while the hearing-impaired participant sought medical advice for their tinnitus, the Deaf participant had never sought medical advice but adapted to ignore their tinnitus and to live with it. They also acknowledged the potential benefits of sound therapy, but this was not accessible to them due to their deafness. The participants' hearing cousin found it shocking to discover that deaf people can also experience tinnitus.

2.3.5 Theme 3: Cochlear implant studies where tinnitus was a secondary outcome

A cochlear implant was the most-commonly reported treatment (primarily for deafness) investigated in participants with deafness and tinnitus (Table 2.4). One record proposed a tinnitus recovery model following unilateral cochlear implantation in severe-to-profound

hearing-impaired adults complaining of tinnitus based on several factors (Todt et al., 2015). Lower pre-operative Consonant-Vowel-Consonant (CVC) score, unilateral localisation of tinnitus, and larger deterioration of residual hearing at 250 Hz were determined to be predictors of tinnitus recovery. Age at surgery and gender were also reported to be predictive of outcome. Tinnitus recovery was reported in 40% (35/87) of included participants.

One study examined tinnitus suppression according to the method of electrode insertion during cochlear implant surgery (Todt et al., 2015). Participants were grouped into four groups according to the route of electrode insertion; group 1: through a scalar change of the position of the cochlear implant electrode from scala tympani to the scala vestibuli; group 2: through perimodiolar electrode insertion in a scala tympani position; group 3: electrode was inserted via scala tympani; and group 4: electrode inserted via scala vestibuli due to obstruction of scala tympani (meningitis, otosclerosis). Tinnitus suppression was observed in 73.6% of those in group 1, 50% in group 2, 60% in group 3, and 87.5% in group 4.

Three records considered tinnitus suppression over time following cochlear implantation. While two records found evidence for tinnitus suppression after a longer period, 1 and 2 years respectively (Tyler, 1995; Dixion et al., 2020), Kim et al. (2016) found significant tinnitus suppression quite early, after 1 month of using cochlear implant.

Three records (Olze et al., 2012(a); Kim et al., 2013; Knope et al., 2016) studied the impact of age, especially older age, on suppression of tinnitus in cochlear implant recipients. Olze et al. (2012a) found that younger patients (age range 19-67) experienced greater suppression following cochlear implantation (pre-implant TQ score was 29.1 while post implant decreased significantly to 21.0), older patients (age range 70-84) also had a reduction in TQ score (pre-implant TQ was 26.3 while post implant decreased to 22.3) but this improvement was not clinically meaningful. The second record reported that the prevalence of tinnitus was higher in the older age group (>40 years) than the younger group (< 40 years). However,

suppression of tinnitus was reported post-implantation in both groups with no new tinnitus being reported in those who did not have tinnitus pre-implantation (Kim et al., 2013). Finally, Knope et al. (2016) found that tinnitus and psychiatric comorbidities were both improved post-implantation in elderly patients over 80 years old (mean TQ pre implant was 18.5 and decreased to 13.2 post implant, which represented a clinically meaningful improvement). Bilateral sequential cochlear implantation was examined in four records (Olze et al., 2012b; Zon et al., 2015; Ketterer et al., 2020; Rødvik et al., 2021) and reported as beneficial for tinnitus. However, newly induced tinnitus was also reported following implantation (in five out of 10 participants) following simultaneous bilateral cochlear implantation (Zon et al 2016). Von Zan (2016) compared unilateral and bilateral cochlear implantation in patients who complained of tinnitus pre-operatively. Sixteen patients were included in their trial (seven received unilateral and nine received bilateral cochlear implants). Tinnitus improvement was measured as a change on THI and TQ scores. Scores on both questionnaires significantly decreased over the post-implant period in both unilateral and bilateral cochlear implant patients. However, a few cases of new tinnitus in patients who did not report preoperative tinnitus (five out of 10 in the bilateral group and one out of 12 in the unilateral group) were also reported.

Olze (2012b) evaluated tinnitus suppression following bilateral cochlear implantation and found that participants who did not benefit from unilateral cochlear implantation improved after their second implant. One record (Rødvik et al., 2021) provided sequential bilateral cochlear implants for annoying tinnitus in the unimplanted ear. THI and VAS Loudness and Annoyance were measured before the second sequential cochlear implant and 2 years after implant (short term) and 7 years post implant (long term). THI scores significantly decreased from 61.3 pre implant to 29.3 after the first implant (SD = 23.5) and then 20.3 (SD = 16.3) after the second implant.

One record examined the introduction of regular cochlear implant programming as a factor in tinnitus suppression (Liu et al., 2016). A sample of 108 patients with pre-operative tinnitus who received one cochlear implant was divided into a control group (n=54) with no regular programming, and a programming group (n=54). The programming group had programming at weeks 6, 8, and 12 post-implantation after activation at week 4 whereas the control group had no regular programming post-activation. Both groups had decreased tinnitus handicap scores on the THI, however, improvement was slower in the control group (Table 2.4). Finally, two records specifically investigated changes in tinnitus characteristics following cochlear implantation. Greenberg et al. (2015) found that tinnitus was suppressed totally or partially in the ear ipsilateral to cochlear implant in 57% and in the ear contralateral to the cochlear implant in 43% of patients when the processor was turned on. Further, Greenberg et al. (2015) reported that humming was the most experienced tinnitus sound reported by severe-to-profound hearing-impaired individuals' pre-implantation (68%) and the frequency of those reporting humming reduced (to 50%) post implantation. Conversely, Di Nardo et al. (2007) found buzzing to be the most reported sound post implantation, followed by whistling, airplane/ship engine, and bells ringing. Di Nardo et al. (2007) found that in a group of individuals pre-implantation, a single sound was present in 13 cases (65%) and multiple different sounds were reported in seven cases (35%). Post implantation, a single sound became the majority, being reported in nine cases (45%) and multiple different sounds were present only in three cases (15%).

2.3.6. Recommendations for future research in the included studies

Authors of the included studies made various recommendations for further research, mostly related to the treatment of tinnitus. Theodoroff & Folmer, (2015) recommended that future studies of rTMS should be conducted to include more patients who have severe or profound hearing loss but who did not want to use hearing rehabilitation devices such as hearing aids or

cochlear implants. Further studies on intracochlear stimulation and electrode insertion specifically to explore its effectiveness in tinnitus suppression and generation of new tinnitus (Todt et al., 2015) and programming parameters in cochlear implant recipients with tinnitus (Sarac et al., 2020) were also recommended. Pan (2009) recommended obtaining estimates of the magnitude of the tinnitus pre-implantation and whether tinnitus burden can be related to hearing improvement post-implantation. Laterality was also recommended to be considered in future studies to differentiate the effects of the cochlear implant surgery and cochlear implant activation on tinnitus perception. Finally, exploring the impact of specific symptoms such as clinically significant insomnia on the severity of tinnitus in cochlear implant recipients, prospective studies to investigate insomnia, depression, and anxiety, and characterising the clinical importance of any residual tinnitus-related symptoms after implantation were also recommended (Pierzycki et al., 2021).

2.4 Discussion

This scoping review catalogued (1) the tinnitus experience of Deaf and severe-to-profoundly hearing-impaired adults, and (2) the assessments and treatments that are offered or have been evaluated in the literature.

2.4.1 Tinnitus experience/impact

Studies used various assessment tools including validated questionnaires which according to NICE guidelines (NICE, 2020) are necessary to assess the impact of tinnitus on patients and guide health care providers towards better management strategies. However, none of the questionnaires reported in the literature have been validated for use in Deaf populations (NICE, 2020). We do not know therefore whether they sufficiently capture the real impact of tinnitus, or the relevant changes in tinnitus severity for this population. Validation studies should explore how pre-existing tinnitus questionnaire scores in a D/deaf population should

be interpreted or develop and validate customised questionnaires or other measures of tinnitus severity and treatment-related changes in this population.

2.4.2 Primary treatment of tinnitus in deaf adults

There were four records primarily concerned with the treatment of tinnitus in Deaf and severe-to-profound hearing-impaired adults, reporting four different treatment approaches, with variable outcomes. One study reported a case involving the treatment of tinnitus with medication for comorbid depression and sleep deprivation. There is therefore no evidence to support medication use primarily for tinnitus (Henton & Tzounopoulos, 2021).

One study reported the use of rTMS which is hypothesised to modulate neuronal activity over a large region of the brain using magnetic fields. This approach has been used extensively in small-scale studies of tinnitus with mixed evidence for its immediate effectiveness (Yang et al., 2021; Denton et al. 2021) and little data on long-term safety, all authors proposing further and larger studies of this treatment approach. As such to date there is a strong recommendation against the routine clinical use of this method, which includes those who are both deaf and have tinnitus (Cima et al., 2019).

A behavioural approach in another case study proved effective in alleviating tinnitus distress (Lindberg, 1998). The effectiveness of the CBT is evidenced for tinnitus management in people with less severe hearing loss, but its effectiveness has not been proven in deaf populations (Cima et al., 2019). Therefore, practice guidelines make no recommendation for CBT in Deaf and severe-to-profound hearing-impaired populations and those with limited conversational ability, and recent systematic reviews make no reference to the use of CBT in deaf patients (Fuller et al., 2020; Landry et al., 2020). Given the proven benefits of CBT for tinnitus, necessary adaptations and trialling CBT in deaf populations would be welcomed.

Electrical ear stimulation for tinnitus was used in one record with comparison to a cochlear implant. Although there was improvement in tinnitus using both approaches, improvements were greater for the cochlear implant.

Whilst most tinnitus treatments involve sound and this requires the ability to hear those sounds, others under investigation may be suitable for trialling in Deaf adults although do not. For example, an open trial of an auditory brain implant (NCT02630589) excludes those with a PTA above 90 dB in the ipsilateral ear, and another open trial on laser light therapy (NCT05374421) excludes anyone with age-related hearing loss or conductive hearing loss. Rationale for exclusions based on hearing loss should be well articulated in trial reports. Beyond any issues with access to sound it is likely that many researchers exclude participants who have severe-to-profound hearing loss in an effort to reduce the number of potential confounders and have a more homogenous study population. Problems with tinnitus may be conflated with those caused by hearing loss (Henry et al., 2015) so this effect may be more pronounced in those with more severe hearing losses.

2.4.3 Cochlear implant studies where tinnitus was a secondary outcome

Unilateral cochlear implantation is recommended for hearing restoration in people with severe-to-profound hearing loss who do not benefit sufficiently from acoustic hearing aids (NICE, 2019; Van de Heyning et al., 2022) Van de Heyning et al. (2022) noted that several hospitals and clinics worldwide offer cochlear implants to address tinnitus in addition to profound hearing loss, but typically under specific conditions or strict criteria. For instance, a hospital in Belgium implants patients with tinnitus only if it is a result of hearing loss. In contrast, a hospital in Austria may implant profoundly deaf patients who do not meet standard criteria if additional benefits beyond hearing restoration are anticipated. These studies either examined overall tinnitus suppression following cochlear implantation or investigated specific mechanisms by which cochlear implants suppress tinnitus, such as

electrode insertion or cochlear programming. They also explored how patient-related factors like age, and implant-related factors such as electrode insertion, programming, and duration of device use, can influence outcomes. Also, for patients receiving a cochlear implant, their residual hearing at 250 Hz can be a positively predictive factor for tinnitus suppression post implantation, which could be beneficial in-patient counselling (Ramakers et al., 2018).

Finally, few records examined time as a factor for tinnitus suppression after cochlear implantation, especially in those patients who received a cochlear implant but continued to complain of bothersome tinnitus and thus received a second sequential implant for their tinnitus (Rødvik et al., 2021). Although tinnitus improved in these studies it is unclear whether this was due to the person developing coping strategies or was part of an adaptation mechanism in the auditory brain due to auditory activation following cochlear implantation.

Tinnitus counselling is an important factor in tinnitus management which is lacking in these studies as well as the need for Deaf and severe-to-profoundly hearing-impaired adults to receive personalized management. A cochlear implant is a feasible method of providing hearing restoration but has also been demonstrated to have some efficacy in tinnitus suppression, although the results are variable and cases of tinnitus induction by cochlear implants were also reported. Hence, tinnitus patients should receive counselling sessions and must engage in the treatment plan.

Research describing advancements in tinnitus management in deaf populations is greatly needed due to significantly increased numbers of cases of severe and profound hearing impairments in combination with improved overall life expectancy. All included studies used one treatment method, however due to the heterogeneity of tinnitus pathophysiology and different personal experiences, researchers are increasingly examining combinations of treatments such as sound therapy, personalised counselling, hearing aids, and CBT. A recent multicentre clinical trial involved a comparison of the effects of the single and combination

therapy, i.e., hearing aids alone or hearing aids and cognitive behavioural therapy, or hearing aids and structured counselling or hearing aids and sound therapy (Schoisswohl et al., 2021). However, it excluded participants with severe hearing loss due to barriers in communication, which again demonstrates the need for research into adapting the existent or developing new management methods for those who are Deaf or have severe-to-profound hearing loss.

2.4.4 Research recommendations

This scoping review highlighted the lack of dedicated tinnitus research involving adults who have severe-to-profound hearing loss. Researchers should clearly justify excluding this population form their tinnitus studies, and where it is not justified, should ensure studies are adequately resourced to be inclusive, and statistical analysis plans adequately consider hearing loss as a potential confounder. To be confident of outcomes it is also important to adequately screen and disambiguate the problems due to tinnitus from those due to hearing loss, e.g., using the Tinnitus and Hearing Survey (Henry et al., 2015). Greater involvement of carers or significant others, the provision of sign interpreters, and the use of accessible media such as text over audio to include D/deaf adults is needed in tinnitus research. Deaf adults should be involved in setting the research agenda, informing study design, and promoting participation, to ensure inclusivity is maximised. Some recommendations for tinnitus research in D/deaf populations have been identified in clinical practice guidelines, e.g., NICE (2020) recommends research to (1) identify the most clinically and cost-effective tinnitus questionnaire to assess tinnitus in people who are d/Deaf, (2) evaluate the clinical and cost effectiveness of amplification devices for people who are d/Deaf, and (3) evaluate the clinical and cost effectiveness of psychological therapies for people who are d/Deaf and have tinnitus-related distress. They will require multiple approaches to evaluate existing, modified, or newly developed tools and treatments. Before these questions can be addressed, qualitative enquiry is needed to understand the lived experience of tinnitus more fully in d/Deaf adults.

This would inform large scale quantitative enquiry (e.g., an online survey) to understand the breadth and scale of tinnitus problems in d/Deaf adults. A formal prioritisation exercise involving d/Deaf adults with tinnitus and clinicians with expertise in deafness and/or tinnitus would elevate the profile of research in this area, as has been done with success for other topic areas within the field of hearing (Fackrell et al., 2019; Ferguson & Henshaw, 2015). Because of resource limitations this review only examined studies available in English. The findings may therefore not generalise to other populations and their experiences where there may be a significant literature published in other languages. For the same reason it is likely that not all interventions that have been trialled for tinnitus in D/deaf adults have been captured. The review was also limited to studies reporting adult populations, so findings and recommendations cannot be applied to d/Deaf child populations. This scoping review aimed to catalogue the experience of, assessment, and treatment of tinnitus in adults who are Deaf or have severe-profound hearing loss. It is evident that there is very limited research in this area. Although this review included many records, most focused on the provision of cochlear implants for severe-to-profound hearing loss, with assessment and measurement of tinnitus as a baseline or secondary outcome. Largely missing in the literature are empirical studies that seek primarily to understand the nature of the experience of tinnitus in people with no or little residual hearing.

Chapter 3 Methodology and general methods

3.1 Introduction

As concluded in Chapter 2, there is limited research on tinnitus in adults who are deaf or have severe-profound hearing loss, including their experience of the condition, and their assessment and treatment. Most studies were concerned with providing cochlear implants for severe-to-profound hearing loss, with tinnitus assessment and measurement being secondary outcomes. The literature lacks empirical studies that primarily aim to comprehend the nature of tinnitus in individuals with little to no remaining hearing. To address gaps in existing research and achieve the aims of this PhD, a pragmatic paradigm was selected (Creswell, 2011). This paradigm bypasses ontological and epistemological debates and focuses on solving real-world problems (Davies & Fisher. 2018). The mixed-methods approach, grounded in pragmatism, combines both quantitative and qualitative methods to produce meaningful results. One of the major advantages of this approach is its ability to tackle complex questions that cannot be adequately answered using a single method (Lund, 2012). Moreover, using a mixed methods approach broadens the range and depth of the investigation, enabling a more thorough examination of the subject matter and yielding robust and validated results (Dawadi et al., 2021; Plano Clark & Ivankova, 2018).

My objective was to conduct a study in both a sample from Saudi Arabia and a sample from the United Kingdom. Before traveling to the UK, I also had a meeting with the Head of Special Needs at King Abdulaziz University, who expressed interest in collaborating on the project and assisting with recruitment. The rationale for selecting two study samples was to broaden the understanding of the tinnitus, and to explore the potential challenges that may arise due to cultural and language differences between the two populations.

3.2 Ethical consideration

Ethical approval for this study was sought and obtained from the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee (study reference: FMHS 254-0521) (Appendix 1).

3.2.1 Confidentiality and anonymity

To ensure participant confidentiality, each participant was assigned a unique identification number during the data collection process. Prior to conducting interviews, participants were provided with an information sheet detailing the study objectives and the personal information that would be needed. Written informed consent was obtained before interviewing or any audio recordings were made. Appendices 2 and 3 show the consent form and invitation letters in both Arabic and English.

3.2.2 Data storage

To ensure that all data were preserved for future analysis, participants' responses during the interviews were recorded in audio format. After each interview, the recordings and transcripts were securely stored, along with the other completed questionnaires, on a password-protected university of Nottingham computer. Additionally, OneDrive was used, using an official email from the University of Nottingham, to store data and to share it with the supervisors. Throughout the study, no data were misplaced or lost.

3.2.3 Withdrawal

The participants were given an option to participate in the study voluntarily and were informed that they could withdraw from the study at any time. One participant from the sample in the UK expressed interest initially but later withdrew from the study before participating in the interview and completing the questionnaires. No reason was given.

3.3 Description of the study

The methodology of this study is presented in Figure 3.1. The study used a concurrent mixed methods design which allows for the collection of qualitative and quantitative data at the same time.

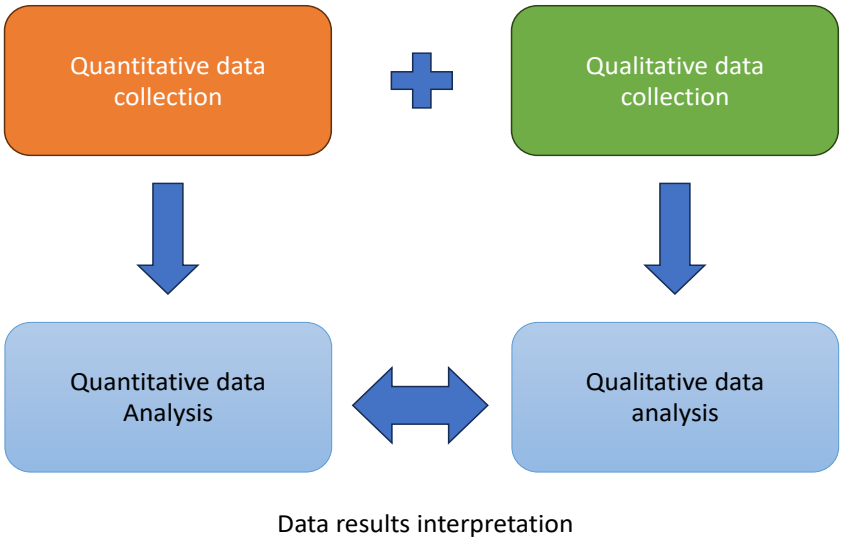


Figure 3.1 Concurrent triangulation mixed-methods design (adapted from Creswell, 2003).

According to Creswell (2003), the concurrent triangulation design is frequently utilised by researchers as it involves the use of two distinct data collection methods. This design aids in confirming and validating findings, while also addressing any limitations that may exist in one method by capitalising on the advantages of the other method. The timeframe for collecting and interviewing participants is shown in Figure 3.2.

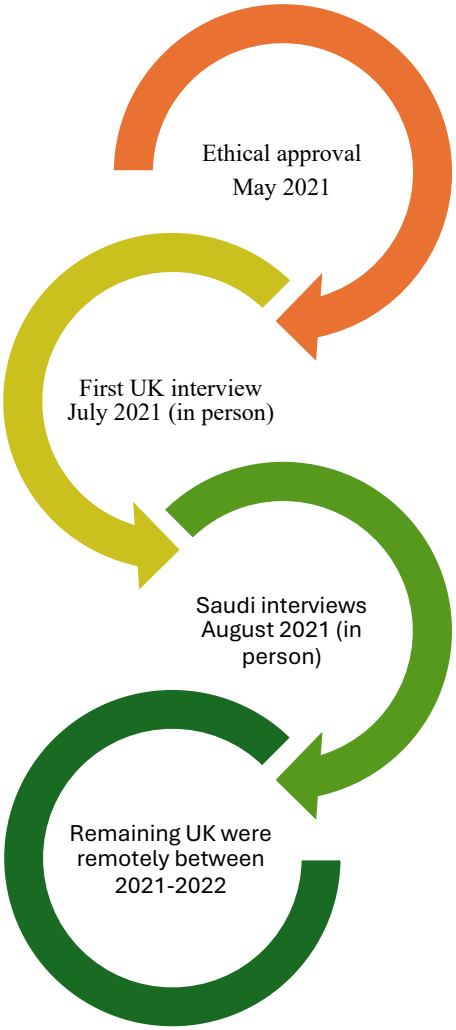


Figure 3.2 Timeframe used in data collection from both study samples.

3.4 Methods

This study utilised quantitative and qualitative methods. The quantitative component of the study involved a basic demographic survey, administration of the Tinnitus Handicap Inventory (THI, Newman et al., 1996) to assess the severity of tinnitus, and the Depression, Anxiety, and Stress Scale (DASS, Lovibond & Lovibond, 1995) to measure these conditions commonly comorbid with tinnitus. These were selected over other questionnaires because they are available and validated in both English and Arabic Barake et al., 2016; Moussa et al., 2017). Additionally, the study incorporated a qualitative component consisting of semi-

structured interviews. These interviews aimed to gain a deep understanding of the tinnitus experience in individuals who are deaf or have severe-profound hearing loss.

3.4.1 Questionnaire measures of tinnitus impact and associated comorbidities

I.Tinnitus Handicap Inventory English version

In 1995, Newman et al. introduced the THI as a clinical tool to measure the impact of tinnitus on various aspects of everyday life. The main items were derived from clinical histories of patients with tinnitus. The primary aim of the THI was to create a short, easily administered, and reliable assessment tool for measuring the impact of tinnitus on different aspects of daily life (Newman et al., 1995). The THI was originally proposed to consist of three subscales: Functional, Emotional, and Catastrophic (Table 3.1). Appendix 4 shows the THI questionnaire.

Table 3.1 THI subscales: Functional, Emotional, and Catastrophic domains assessed in tinnitus severity measurement

THI subscale/ Items no	**Main theme**
Functional subscale (11)	Limitations in mental, social/occupational, and physical health
Emotional subscale (9)	Affective response to tinnitus (anger, frustration, irritability, and depression)
Catastrophic subscale (5)	Feelings of desperation, inability to escape from tinnitus, perception of having a terrible disease, lack of control, and inability to cope

The THI was initially composed of 45 items but was later shortened to 25 items. Eighty-four patients complaining of tinnitus were included in the first creation of the 45-item alpha version and then 66 patients with tinnitus completed the second 25-item beta version.

Participants were asked to respond to each item using a three-point scale: Yes (4 points), Sometimes (2 points), and No (0 points). The total score is calculated by summing the scores from all items across all subscales. Higher scores indicate a higher level of tinnitus impact (Table 3.2), with Grade 4 and above possibly associated with psychological problems (McCombe et al., 2001).

Table 3.2 Tinnitus Handicap Inventory Scores and grades.

SCORES	GRADE/ SEVERITY	DESCRIPTION
0-16	Grade one/ Slight	Tinnitus is only heard in a quiet environment and does not interfere with sleep or daily activities
18-36	Grade two/ Mild	Tinnitus can be easily masked by environmental sounds
38-56	Grade four/ Moderate	Tinnitus may be noticed even in the presence of background noise and can interfere with sleep and quiet activities
58-76	Grade five/ Severe	Tinnitus almost always heard, leading to disturbed sleep and negatively affecting daily activities
78-100	Grade six/ Catastrophic	Tinnitus with all symptoms at a severe level or worse and is rare

As with any questionnaire, validation of the incoming data is important, and the finding must be reliable and valid (Bowling, 2014). Reliability refers to the consistency and reproducibility of an instrument used on a specific sample and the use of this instrument remains consistent over time and across individuals. It includes measures of internal consistency (Cronbach's alpha), test-retest reliability, and interrater reliability. This consistency is quantified by the reliability coefficient (Cronbach's alpha) which ranges from 0 to 1, with a value of 1 indicating no error. On the other hand, the concept of validity pertains to how accurately an

instrument measures what it is intended to measure (Bowling, 2014). Validity is typically evaluated using the three Cs: Content (the ability of an instrument to accurately measure what it is intended to measure), Criterion (comparing the measure to another measure that is already considered valid), and Construct (the confirmation that an instrument accurately measures the intended underlying concept) (Heale & Twycross, 2015). In the context of health studies, the definition of validity may be adapted since questionnaires often assess subjective conditions like quality of life, depression and pain, which cannot be objectively measured. Hence, validity, as previously mentioned, refers to the extent to which an instrument provides valuable information for a specific purpose, rather than being an inherent characteristic of the test itself (Streiner & Kottner, 2014).

The THI demonstrated excellent internal consistency with a Cronbach's alpha coefficient of 0.93, indicating that it consistently measures a single variable. Internal consistency of the functional subscale was 0.86, for the emotional subscale was 0.87, and for the catastrophic subscale was 0.68. To assess convergent validity, scoring on the THI was compared to the Tinnitus Handicap Questionnaire (THQ, (Kuk et al., 1990)). The THQ consists of three factors measuring the physical, emotional, and social consequences of tinnitus, as well as the patients' hearing ability and their personal view of tinnitus. The THI showed comparable dimensions to the THQ, with a correlation coefficient of 0.78 on their global scores, meaning they measures a similar/the same construct. Construct validity was assessed by comparing scoring on the THI with the Beck Depression Inventory (BDI, Beck et al., 1961), a 21-item scale measuring specific behavioural manifestations of depression, and the Modified Somatic Perception Questionnaire (MSPQ, Main, 1983), a 13-item scale designed to measure somatic and autonomic perception.

The THI measures the psychological impact of tinnitus rather than treatment outcomes, as supported by a study conducted by Salavati et al. (2013) in 156 patients with chronic tinnitus.

Their claim was that tinnitus is a subjective symptom and its severity correlates more with pain or insomnia, rather than audiometric parameters. The study also found that a significant number of patients had psychiatric disorders and suggested that THI total scores above 36 should prompt audiologists to consider psychiatric referral.

Fackrell et al. (2014) evaluated the psychometric properties of the THI and other tinnitus questionnaires. The results showed that the functional and emotional subscales of the THI had high internal consistency (Cronbach's alpha = 0.86 and 0.87, respectively), while the catastrophic subscale had lower internal consistency (Cronbach's alpha = 0.68). This discrepancy in internal consistency may be attributed to the limited number of items (5) in the catastrophic subscale compared to the other two subscales. The THI was, therefore, considered as a unidimensional tool, suggesting that clinicians and researchers can rely on its overall scores to measure tinnitus severity as also agreed by (Goss et al., 2020). Goss et al. conducted a study with 1,115 patients with tinnitus, aged 19 to 84, and employed confirmatory factor analysis and item response theory to evaluate the THI dimensionality. Their findings also indicated that the THI is a reliable unidimensional scale for evaluating tinnitus severity, with clinicians and researchers advised to rely only on its overall score for severity assessment.

II. Tinnitus Handicap Inventory Arabic version

The process of adapting a questionnaire for translation into different languages should follow six steps, as outlined by Hall et al. (2018a). Step 1 is preparation: before starting the translation process, it is important to determine whether there is already a translated version availableClick or tap here to enter text.. The second step involves translating the source into the target language. The questionnaire should be translated independently by at least two bilingual translators. Any discrepancies between the translations should be discussed to create a consolidated version. The third step is to translate the target language version of the

questionnaire back into the source language to identify and address any differences. Committee review will follow, which involves a multidisciplinary team, including a bilingual translator and a clinical expert, which reviews the steps taken and gives their approval or not. Prior to the final stage, field testing will be conducted to assess the viability of the translated questionnaire. This involves two steps: first, recruiting a small sample of patients from the target population to evaluate the questionnaire's cultural suitability, and, secondly, assessing the translated version to ensure it meets the necessary requirements. This assessment can be achieved through cognitive debriefing, which entails conducting a qualitative pre-test process of the translated instrument in the target language using semi-structured interviews or focus groups. Additionally, pilot testing is conducted, which involves the quantitative administration of the complete translated questionnaire to ensure that wording, instructions, items, response scale, size and length are appropriate (Hall et al., 2018a).

Lastly, it is important to review the results from piloting the translated questionnaire and make any necessary amendments or proofreading. All reports and documents should be sent to the original source language developer and approval should be sought if applicable. This step will help reduce the need for multiple translations of the questionnaire.

Baraka et al. (2016) undertook the translation of THI into Arabic by following the previously mentioned steps and obtaining permission from the original publisher to translate the THI. (Appendix 5). Two bilingual native Arabic-speaking translators, one of whom was a physician, independently translated the original THI from English to Arabic. Subsequently, a back translation from Arabic to English was conducted by two native-English speakers who were unaware of the existence of the English version. The translated version was then pilot tested on 100 native Arabic-speaking patients with tinnitus lasting more than three months. The internal consistency of the translated total item scores was found to be similar to that of the original THI English version (=0.93) (Barake et al., 2016). No validity testing was done.

III.Depression, Anxiety and Stress Scale English version

The Depression Anxiety Stress Scale (DASS) was introduced by Lovibond and Lovibond (1995) following a study conducted between 1979 and 1990 to create self-report scales for depression and anxiety. An additional scale of stress was added during the testing phase of the depression and anxiety scales. The objective of the DASS is to assess the severity of symptoms in the three categories experienced within the previous week (Appendix 6). It comprises 42 items that assess various aspects of depression, anxiety and stress. Responses are rated on a Likert scale of 0-3 where 0 indicates 'Did not apply to me at all' and 3 indicates 'Applied to me very much, or most of the time'.

Total scores are calculated by summing the scores of the 14 items in each subscale. A shorter version of the DASS, known as DASS-21, includes only 21 items (7 items in each subscale), and the scores are multiplied by 2 to obtain the full-scale scores (Lovibond & Lovibond, 1995). Items selection was based on three key criteria: strong factor loadings, coverage of all subscales (depression, anxiety, and stress), and ensuring that the DASS-21 scores closely matched half of the DASS-42 scale scores. These criteria helped maintain the psychometric properties of the original DASS while creating a more efficient tool that could be administered in half the time. To ensure comparability with the full DASS-42, the DASS-21 scores should be multiplied by 2 when interpreting results.

Total scores and interpretations for each subscale are shown in Table 3.3.

Table 3.3 Depression, Anxiety and Stress Scale total scores for each subscale and grade.

	DEPRESSION	ANXIETY	STRESS
NORMAL	0-9	0-7	0-14
MILD	10-13	8-9	15-18
MODERATE	14-20	10-14	19-25
SEVERE	21-27	15-19	26-33
EXTREMELY SEVERE	28+	20+	34+

Since the DASS measures multiple constructs in the same questionnaire, reliability of this questionnaire is assessed using factor analysis. To assess factor structure, principal component factor analysis was used, and most items showed high to moderate loading on their own factors and low loading on other two factors (Lovibond & Lovibond, 1995). Correlation factors were as follows: Depression-Anxiety r=0.42, Anxiety-Stress r=0.42 and Depression-Stress r=0.39), indicating the scales all measure different constructs.

The second approach to assessing factor structure was confirmatory factor analysis (statistical analysis is conducted to evaluate the predetermined structure of items within a grouped construct and determine the level of fit) (Humble, 2020). Three factor models (single, two-factors, and three factors) were tested with better results in validation of the three subscales with final Phi coefficients (which assess the strength between the three factors) of: Depression-Anxiety 0.61, Anxiety-stress 0.76, and Depression-Stress 0.62. Correlation between DASS and BDI total and subscale scores were also tested. The anxiety subscale of the DASS and BDI were highly correlated (r=0.81), even more so than the BDI and depression subscale of the DASS (r=0.74) (Lovibond & Lovibond, 1995). The strong

correlation at the level of anxiety highlights the connection between long-lasting anxiety and the immediate fear response. The DASS-21 was used in this study.

IV. Depression, Anxiety and Stress Scale Arabic version

The DASS has been translated into many languages including Arabic. Moussa et al. (2017) translated and examined the psychometric properties of the DASS-42 in Arab immigrants in Australia. The process of translation followed four phases (Moussa et al., 2017) (Appendix 7). Phase 1 of the translation involved a professional translator who was employed to first translate the DASS-42 into Arabic followed by a blinded back translation into English by another professional translator. In phase 2, a committee consisting of the primary investigator of the study and another Arabic-speaking mental health professional compared the back translated version with the original version and reviewed the Arabic translation in detail. Field trials were conducted on the initial Arabic draft of the study questionnaire. Feedback and comments were collected from the study participants, as well as from Arabic-speaking mental health professionals, to ensure the questionnaire's adequacy. In phase 4, participants in a bilingual sample were sent both the Arabic and English versions of DASS 1 week apart in random order. Confirmatory factor analysis was used to test factors structures similar to the original DASS and showed that Phi coefficients (assessing the strength between two variables) between Depression-Anxiety 0.91, Anxiety-Stress 0.91 and Depression-Stress 0.92 were high, indicating a strong improvement in the fitted model. The DASS-21 is also available in Arabic.

V. Rationale for using the Tinnitus Handicap Inventory and Depression, Anxiety and Stress Scale.

To assess tinnitus severity, the THI was selected based on previous study findings (Chapter 2), where the THI was used in the assessment of tinnitus by the highest number of included

records in the scoping review (n=17). Its compatibility with the study participants, as it does not evaluate hearing status, influenced this choice. This allowed for the integration of quantitative data from the THI with qualitative data from semi-structured interviews.

With respect to assessing tinnitus comorbidities, the DASS-21 (short version) was chosen due to its ability to assess frequent co-occurrence of tinnitus symptoms (depression, anxiety, and/or stress), as well as its widespread use in non-clinical settings. It assesses depression, anxiety, and stress within a single instrument, allowing for a comprehensive evaluation of these related psychological states in tinnitus patients. Both questionnaires (THI & DASS-21) are available in Arabic and English.

VI. Quantitative analysis

Statistical analysis of quantitative data was conducted using Prism version 9. The mean, standard deviation and range of questionnaire responses were calculated. To assess the significance of differences between the two study populations, non-parametric tests (Mann-Whitney test) were used owing to the small sample sizes.

3.4.2 Semi-structured interviews: Tinnitus experience

Interviewing is a method used to gather qualitative data by asking questions and receiving responses from participants. To explore the experience of tinnitus, a semi-structured interview technique was selected. This method enables interviewees to describe phenomena while also allowing investigators to analyse responses and collect specific information (Cohen & Crabtree, 2008; Zohrabi, 2013).

Before the study, an interview guide was developed. No piloting was carried on any control participants due to the COVID-19 pandemic. A simple demographic survey was conducted to gather information about the participants, including their age, ethnicity, age at onset of hearing loss, and the cause of their hearing loss. The survey also inquired about the use of

any assistive devices, such as hearing aids or cochlear implants. Additionally, participants were asked about their preferred mode of communication. Participants were provided with a participant information sheet and consent form and were informed that their participation was completely voluntary and that they could withdraw at any time.

I. Participant criteria

The target population was deaf and severely-to-profoundly hearing-impaired adults. The inclusion criteria were: 1. Adults aged 18 years old and over, 2. Bilateral deafness or severe-profound hearing impairment, 3. Chronic tinnitus defined as tinnitus with a duration of at least 6 months. Exclusion criteria were: 1. Children, 2. Normal or mild-to-moderate hearing loss or unilateral hearing loss, 3. Objective tinnitus or no history of tinnitus.

II. Sampling and recruitment

To serve the research purpose and questions, two sampling methods were utilised: snowball sampling, where each participant can recruit another participant, and convenience sampling, which involves identifying participants who are easily accessible to the researcher (Taylor et al., 2017). While probability samples are typically sought-after in quantitative research, qualitative research relies on purposive sampling. However, it is important to achieve data richness, which can be accomplished through saturation. Saturation occurs when no new information or themes can be added to the body of knowledge (Patton, 1999). It is a challenging process, and there are several methods that can aid in reaching saturation, such as code saturation (indicating that the researcher has captured all relevant information) and meaning saturation (indicating that the researcher has fully understood the data) (Hennink et al., 2017). However, Braun and Clark (2021) argue that saturation is difficult to achieve and may require the use of additional theoretical frameworks for proper implementation. Although a mixed-method approach was selected, the main aim of these studies was to

explore the lived experience rather than validate quantitative measures. As such the study was powered against the qualitative component, where the aim is to reach a saturation point. Once saturation is achieved, additional cases typically won't provide much new information, so the sample becomes rich and sufficient for analysis. Many qualitative studies highlight the importance of saturation to ensure that the themes identified are well-supported and comprehensive where other against. A systematic review of power in qualitative studies indicates a sample of between 9 and 17 is typically required to achieve data saturation (Hennink and Kaiser, 2022). In this study I therefore aimed to achieve a minimum sample in this range, with ethical approval to recruit up to 20 participants per group.

Furthermore, because these studies were conducted during the COVID-19 pandemic, recruitment posed additional challenges, particularly with hard-to-reach populations like the Deaf community in the UK. Recruiting participants from this group proved to be more difficult than usual, and this limited the sample available in the PhD timeframe.

To recruit participants for the study in Saudi Arabia, multiple methods were utilised. Firstly, an advertisement was distributed to the special needs division at King Abdul-Aziz University and the Deaf Organization Society. The university has a dedicated unit for students with various disabilities, including immobility, vision impairment, and hearing impairment. I also sent an email containing the invitation letter to the head of the centre.

The Jeddah Deaf Club was also approached, a charity organisation that provides socialisation and support for possible candidate participants. I reached out to the head of the centre and informed some of the participants during their weekly gathering at the centre about the opportunity to join the study.

In the UK, comparable methods were employed. Initially, participant information sheets and invitation letters were emailed to eligible individuals who were registered on the NIHR

Nottingham Biomedical Research Centre database, inviting them to participate in the research. Once COVID-19 restrictions were eased and it was possible to contact people directly, I also reached out to the Nottinghamshire Deaf Society in March 2022. The secretary was provided with materials such as participant information sheets and invitation letters, allowing them to inform any interested individuals about the opportunity to join the study.

III. Study settings

In the case of the Saudi Arabia sample the participants completed the questionnaires in a room supplied by the university with the presence of a Saudi Arabian Sign Language (SASL) interpreter. All interviews were conducted in a quiet meeting room at either the King Abdul-Aziz University or the Deaf Society. All participants from Saudi Arabia needed a sign language interpreter and the interpreters were provided either from King Abdul-Aziz University or the deaf community organisation.

In the UK sample, 11 of 13 interviews were carried out remotely, one participant attended the interview in person at Ropewalk House, a hospital building in Nottingham, UK, and one participant responded to the interview questions via email. A British Sign Language interpreter was provided for one participant, while the remaining participants relied on assistive devices including cochlear implants and hearing aids and were skilled lip-readers. The choice of interview platform was left to the participant. Some participants preferred Zoom due to its live transcript feature, while others opted for a WhatsApp video call.

IV. Data collection

Participants were thanked for agreeing to take part in the study, and a few demographic questions were asked including age, ethnicity, working status, onset of hearing loss and its cause. Finally, participants were asked about their use of assistive devices and their preferred mode of communication. The interview then proceeded with three main parts (Appendix 8):

1. Tinnitus characteristics: Participants were asked about the onset of their tinnitus, the nature of the sound they experienced, if they knew the cause of their tinnitus, the location of the sound, its frequencies, and whether they sought medical advice for their tinnitus or not.
2. Tinnitus impact: In this section, questions were asked about how tinnitus affected the participants personally, including its impact on their sleep, work and quality time with their family. Participants were also asked whether they avoided certain situations because of their tinnitus and whether they preferred isolation. Additionally, they were asked about their thoughts on what triggers their tinnitus and what makes it worse or relieves it.
3. Tinnitus management: Participants were asked about the methods they used to manage their tinnitus and whether they received any support from others. Finally, their opinions on future tinnitus management and research were sought.

All interviews conducted verbally were audio-recorded, and no interviews were repeated. The interviews were scheduled to last for 1 hour each.

V. Qualitative data analysis

Framework analysis was the method of choice to analyse qualitative study data. It is a technique developed by Jane Ritchie and Liz Spencer in the early 1980s and which was specifically designed for researchers involved in applied and policy-making work in social science and was later used in health sciences (Ritchie & Lewis, 2003). It was chosen because it follows a systematic and orderly procedure that is applied step by step during the analysis process (Gale et al., 2013). Moreover, it organises data into predefined categories within a matrix, which aids in the systematic exploration of the data for easy comparison between datasets (Parkinson et al., 2016).

Thematic analysis, as created by Braun and Clarke, allows a flexible approach in exploring the data to the extent that the researcher can reflect on the data meaning and shape their analytical strategies (Braun & Clarke, 2019). However, framework analysis demands a consistency between the analytical framework to ensure a standardised and transparent analysis for reproducibility and comparison (Mohd Arifin et al., 2019).

The framework analysis used in this thesis consists of five main steps, as follows:

Step 1: Data familiarisation

All audio recordings were transcribed and were imported into N-Vivo software. The coding team (LA, DH & MS) began the initial stage of coding by reviewing the interview transcripts and determining which codes were appropriate.

The principal investigator read and listened to interviews several times to immerse in the data. To facilitate this process, three transcripts were randomly selected for piloting. Subsequently, the team engaged in several discussions to establish codes and their definitions.

Step 2: Identifying a thematic framework

Once the codes were established, a thematic framework was developed to identify significant patterns and themes within the data. These themes were subsequently applied to address the research objectives and provide insight into specific issues. The remaining interview transcripts were coded according to these predefined themes, which were categorised into three key areas: the characteristics of tinnitus, the impact of tinnitus, and healthcare provision for tinnitus treatment. This process involved classifying the themes based on the predetermined categories, which were informed by the research objectives and the interview guide. The interview guide questions proved instrumental in guiding the identification and categorisation of these themes.

Step 3: Indexing

Once codes and themes were finalised, the thematic framework was applied consistently across all textual data. Indexing involved coding or labelling pertinent segments of the data (e.g., interview quotes) according to the identified themes. It was essential to ensure consistency at this stage, ensuring that all relevant data were correctly aligned with the appropriate themes. Appendix 9 shows the agreed thematic framework in the form of the codes and themes used in the analysis.

Step 4: Charting

Data that were indexed in stage 3 were next organised into several charts based on the identified themes. A matrix was used to organise the answers given by each participant and to attribute those answers to the most fitting theme and subthemes. A matrix (visual representation that allowed for easy comparison across different sources or cases) was used to structure the responses provided by each participant, linking these responses to the most relevant theme and subthemes. For example, columns represented themes, and rows represented individual participants or cases. This charting step was essential as it enabled the researcher to identify patterns, relationships, and trends across the data, facilitating a more comprehensive understanding of the findings.

Step 5: Mapping and interpretation

In this final stage, charts were analysed to identify the key characteristics. This analysis allowed for a systematic and clear understanding of how tinnitus began for the research participants, its impact on them, and any methods that participants had used to attempt to overcome it.

VI. Reflexivity and personal motivation

Reflexivity is important in acknowledging how the researcher and the research process may have influenced the collected data, including the influence of prior assumptions and

experiences (Mays & Pope, 2000; Pope et al., 2000). Since 2010, I have been working as an audiologist at the Audiology and Balance clinic in King Abdul-Aziz University Hospital in Jeddah, Saudi Arabia. In my role, I have had the opportunity to see a wide range of patients with different levels of hearing loss. I am responsible for diagnosing their condition, investigating the underlying cause of their hearing loss, educating them about preventative measures, and providing treatment options. Additionally, I assisted patients in selecting suitable hearing aids and, if necessary, consider the possibility of cochlear implantation. As a physician, I have a keen interest in attending conferences and workshops to stay updated on the latest advancements in tinnitus treatment. During the British Society of Audiology (BSA) conference in Manchester in 2018, an intriguing question was raised regarding the experience of tinnitus in individuals who are deaf or have profound hearing loss. To my surprise, it was revealed that they do indeed experience tinnitus, similar to those with mild to moderate hearing. This revelation sparked my curiosity about why these individuals may not communicate about their tinnitus. Is it because no one has asked them about it? Or could it be a communication barrier?

Chapter 4 The lived experience of tinnitus in deaf and severely-to-profoundly hearing-impaired Saudi Arabian adults.

4.1 Introduction

As mentioned in Chapter 1, tinnitus is a highly prevalent condition, affecting approximately 14.4% of the global population. In recent years, several studies have investigated the prevalence of tinnitus within the Saudi community (Alanazi, 2024; ALqarny et al., 2021; Alsanosi, 2011; Musleh et al., 2020). These studies varied in scope, methodology, and sample population. For example, Alsanosi (2011) examined tinnitus prevalence among patients attending an otology clinic using a retrospective design and the Arabic THI (Alsanosi, 2011). The study found that 43% of the 100 patients attending the clinic reported tinnitus. Notably, a significant proportion of these individuals experienced severe tinnitus, particularly males, those with hearing loss, and those with a longer duration of tinnitus.

In another cross-sectional study, Musleh et al. (2020) explored tinnitus prevalence among 400 health science students at King Khaled University in Abha, Saudi Arabia. The students were screened for tinnitus using an adapted version of the National Health and Nutrition Examination Survey (NHANES). The study revealed that 28.5% (n=114) of participants had experienced tinnitus at some point, while 19.5% (n=78) reported symptoms within the last 12 months (Musleh et al., 2020). Additionally, 51.8% of those with tinnitus reported it as bilateral. Similarly, a study conducted by ALqarny et al. (2021) across four centres in Jizan, Saudi Arabia, found that 43.1% of the participants had tinnitus, with 72% experiencing bilateral hearing loss (ALqarny et al., 2021).

A more recent study by Alanazi (2024) aimed to estimate the prevalence of tinnitus and examine the experiences of those affected within the Saudi population. This cross-sectional study was conducted between November 2023 and June 2024, with patients attending the

audiology clinic at King Abdulaziz Medical City in Riyadh (Alanazi, 2024). The study included adults aged 18-90 who sought treatment for various complaints, including hearing loss, tinnitus, and vertigo. Participants completed a comprehensive questionnaire that gathered data on demographics, tinnitus experiences, the impact on quality of life, and treatment satisfaction. The study found that 6.5% of the sample (n=320/4860) reported tinnitus, with a slightly higher prevalence among men (6.9%) than women (6.2%). Notably, 69.7% (n=223) of participants also had hearing loss, and noise exposure was identified as the leading cause of tinnitus in 43.2% of cases.

Studying tinnitus within the Saudi community is particularly important due to the high prevalence of hearing loss in the country (GaStat, 2017). According to a 2017 government disability report, hearing loss was identified as the third most common disability in Saudi Arabia, following mobility and vision impairments. The survey, which covered 33,575 households nationwide, revealed that 7.1% of the population experienced some form of hearing-related difficulty. At that time, the total population of Saudi Arabia was 32,552,336. This issue is even more relevant today, given the significant population growth in Saudi Arabia, which has increased to approximately 37.99 million by 2025 (MacroTrends, 2025). Understanding and addressing tinnitus and hearing loss within this growing population is critical for improving public health outcomes and quality of life.

In addition to the high prevalence of hearing loss, hereditary hearing impairment is notably common in Saudi Arabia, with estimates ranging from 36.6% to 66.07%. This is largely attributed to the high rate of consanguineous marriages in the region (Almazroua et al., 2020; Zakzouk, 2002). Zakzouk's epidemiological study (1990-2000) revealed that severe and profound hearing loss represent significant portions of cases in the population, with profound deafness affecting 1 in 1000 individuals with hearing impairment. These findings are consistent with global patterns of severe and profound hearing loss (Haile et al., 2021a).

Furthermore, consanguineous marriages—especially those between first cousins—carry a 3.5 times higher risk of congenital sensory hearing loss (Almazroua et al., 2020).

4.1.1 Aim

The purpose of this mixed method study was to investigate the lived experience of tinnitus in deaf and severe-profound hearing-impaired adults in Saudi Arabia.

4.1.2 Objectives

Tinnitus impact has not been studied in D/deaf and severe-profound hearing-impaired adults, hence the objectives were:

1. To investigate tinnitus severity using the Tinnitus Handicap Inventory (THI) questionnaire.
2. To investigate presence of tinnitus-associated comorbidities using the Depression, Anxiety and Stress Scale 21 (DASS-21).
3. To investigate tinnitus lived experience through semi-structured interviews.
4. To triangulate the study results.

4.2 Methods

4.2.1 Quantitative data

Quantitative data consisted of basic demographic surveys to explore participants' age, cause of hearing loss and type and finally preferred mode of communication followed by tinnitus impact and comorbidities questionnaires. The Arabic version of the THI was selected to evaluate the severity of tinnitus in the participants included in the study (Barake et al., 2016). The THI is a clinical tool consisting of 25 items that assess the impact of tinnitus on various aspects of daily life. Participants were asked to respond on a three-point scale, with "yes" receiving 4 points, "sometimes" receiving 2 points, and "no" receiving 0 points. Total score

was calculated by summing the scores from all items across all subscales, with higher scores indicating a greater level of tinnitus impact. It is classified into five categories denoting handicap severity: no handicap (0-16), mild handicap (18-36), moderate handicap (38-56), severe handicap (58-76) or catastrophic handicap (78-100).

The Arabic version of the Depression, Anxiety and Stress Scale 21 (DASS-21) was chosen (Moussa et al., 2017) to assess the severity of symptoms in the three categories experienced within the previous week. There are 21 items (7 items in each subscale), and the scores are multiplied by two to obtain the full-scale scores (Lovibond & Lovibond, 1995). Total scores are calculated by summing the scores of the 14 items in each subscale.

4.2.2 Qualitative data

The qualitative component of this study consisted of an interview guide that addressed three main aspects of tinnitus as described in Chapter 3. Data were collected using a face-to-face interview where all participants except one required a Saudi Sign Language interpreter, which was provided to all participants.

4.3 Results

4.3.1 Quantitative findings

Thirteen participants were included (five males and eight females), and the average age of participants was 43.3 years (SD=11.7, range 23-60). Summary demographic information can be found in Table 4.1. Twelve participants were deaf since birth and one participant experienced hearing loss from the age of 10 years. With respect to the cause of haring loss, seven participants reported that their hearing loss was caused by infection, five reported genetic factors, and one participant reported medication received by their mother during pregnancy as the cause of their deafness. Eight participants used hearing aids; six had

bilateral hearing aids and two unilateral hearing aids in their right ear. Five participants did not use any assistive devices. All participants were using Saudi Arabian sign language as a mode for communication, with three using lip reading in addition and one using oral language.

Table 4.1 Demographic summary of included SA participants

ID number	Age (years)	Gender	Ethnicity	Onset of HL (age or life stage)/ type of HL	Cause of HL	Mode of communication	Use of assistive devices
P^{SA1}	39	Male	Saudi/Arab	10 years/ post-lingual	Infection	Oral + sign language	Unilateral hearing aid – right ear
P^{SA2}	52	Male	Saudi/Arab	Since birth/ pre-lingual)	Infection	Sign language	Bilateral hearing aids
P^{SA3}	38	Female	Saudi/Arab	Since birth/ pre-lingual	Genetic	Sign language + Lip-reader	Bilateral hearing aids
P^{SA4}	59	Female	Saudi/Arab	Since birth/ pre-lingual	Antenatal medication	Sign language	None
P^{SA5}	37	Male	Saudi/Arab	Since birth/ pre-lingual	Infection	Sign language	None
P^{SA6}	49	Male	Saudi/Arab	Since birth/ pre-lingual	Infection	Sign language	None
P^{SA7}	60	Female	Saudi/Arab	Since birth/ pre-lingual	Infection	Sign language	Bilateral hearing aids
P^{SA8}	46	Female	Saudi/African	<1 year old/ pre-lingual	Childhood infection	Sign language + Lip-reader	Bilateral hearing aids
P^{SA9}	38	Male	Saudi/Arab	Since birth/ pre-lingual	Genetic	Sign language	Unilateral hearing aid – right ear
P^{SA10}	23	Female	Sudanese/African	Since birth/ pre-lingual	Genetic	Sign language	None
P^{SA11}	32	Female	Saudi/Arab	Since birth/ pre-lingual	Genetic	Sign language	None
P^{SA12}	58	Female	Saudi/African	< 1 year old/ pre-lingual	Childhood infection	Sign language	Bilateral hearing aids
P^{SA13}	32	Female	Pakistani/Asian	Since birth/ pre-lingual	Genetic	Sing language + Lip-reader	Bilateral hearing aids

The average THI score of all participants was 19.5 (SD=20.2), which equated an average mild handicap. Six participants had mild tinnitus handicap (score between 18 and 36 points), five had no or slight tinnitus handicap (scores between 0 and 16 points), one participant had moderate (score between 38 and 56 points) and one severe handicap (score between 58 and 76 points). None of the participants had catastrophic tinnitus.

There were several questions that the study participants faced difficulties with when they were completing the questionnaire. Item 2 ("Does the loudness of your tinnitus make it difficult for you to hear people?") was irrelevant to their condition because they are deaf. Further, items 5 ("Because of your tinnitus are you desperate?"), and 21 ("Because of your tinnitus do you feel depressed?") were seen as having similar meaning to each other.

The mean score on the DASS 21-D (symptoms related to depression) was 7.2 (SD=9.2) which indicates no depression. Ten participants fell into that category. Two participants had a moderate depression (scores between 14 and 20 points) and one had extremely severe depression (score above 28 points).

Scores on the DASS 21-A (symptoms related to anxiety) scale were more variable. The mean score on DASS 21-A was 7.7 (SD=9.7) which indicates a score between no- and mild anxiety. Six participants had scores falling into the no anxiety category (scores between 0 and 7 points), three had mild anxiety (scores between 8 and 9 points), two had moderate anxiety (scores between 10 and 14 points) and two had extremely severe anxiety (scores over 20 points).

The mean score on the DASS 21-S (symptoms of stress) was 10 (SD=10.2). Ten participants had scores indicating no stress, one indicating moderate stress (score between 19 and 25 points) and two had scores indicating severe stress (scores between 26 and 33 points).

4.3.2 Qualitative findings

Three overarching themes were derived from the data. These were Characteristics of tinnitus, Tinnitus impact, and Healthcare provision to treat tinnitus.

I. Characteristics of tinnitus

Participants shared their experiences of tinnitus, describing its sound characteristics, location, and potential causes. Six participants recalled their first experience with tinnitus during childhood, while two could not pinpoint the exact age of onset. The rest reported tinnitus onset ranging from their early 20s to more recent occurrences. One participant specifically attributed the onset of their tinnitus to receiving a COVID-19 vaccination. All prelingually deaf participants who could recall the onset of their tinnitus experienced it later in life, with the earliest being at 10 years old. The only post lingually deaf participant in the sample experienced tinnitus at the same time as his hearing loss.

For many participants, the initial experience of tinnitus was met with uncertainty, as they sought validation from family members and friends. One participant, for example, turned to his mother and friends to confirm whether the sound he was hearing was real. The unfamiliarity of the sound and whether it was external or something only they could hear resulted in fear and confusion.

"The first time I heard my tinnitus; I was 11 years old. It started after I lost my hearing". P^{SA1}

"At school. [I] was going to school every day and suddenly, [I] heard tinnitus in my ear and [I] was wearing the hearing aids and [I] didn't know what that sound was. [I] asked the girls: What is this sound?" P^{SA10}

"[I] heard it then [I] went to her mother to tell her. [I] told her [I] heard a strange thing".

P^{SA11}

"The first time [I] heard the sound was like a sound of footsteps, [I] thought it was coming from the outside then [I] got used to it". P^{SA4}

Tinnitus sound characteristics were also variable among participants although they usually reported one single sound such as buzzing, bell ringing, or 'blowing of air like air conditioner'.

Five participants experienced tinnitus in both ears. Three participants specifically mentioned that their tinnitus was in their left ear, and two stated it was in their right ear. Three participants were unable to determine the location of the sound in their ears or head.

"I can't focus to discover which side is it or both. I can't determine". P^{SA1}

Many participants expressed uncertainty about the cause of their tinnitus. However, three participants offered varying explanations for the potential triggers of their tinnitus. One participant mentioned that their tinnitus returned after receiving the COVID vaccination, following a period of complete resolution.

"[I] used to have tinnitus, and it subsides, however, after [I] got my COVID vaccine, the tinnitus came back". P^{SA7}

Some participants reported bodily sensation such as headache and dizziness co-occurring with tinnitus.

"*At first, I got the sound (tinnitus sound) and then I get really dizzy".* P^{SA1}

"Every time [I] had tinnitus, [I] became dizzy". P^{SA12}

"While [I] was listening to music sound in a TV program series, [I] started to hear the tinnitus sounds and [I] felt a headache... so, [I] went to relax but suddenly, a strong drum

sound came, and [I] turn my head to look for it. Now [I] don't hear any drum sound but different sound like blowing in the air". P^{SA8}

One participant experienced tinnitus that was consistently accompanied by a sudden loud sound, followed by severe nausea and vomiting. This condition was so severe that she had to be immediately taken to the emergency department.

"[I] feel something like a balloon is exploded, then the sound becomes like [TEEET] and it increases like someone annoying [me] and shouting. [I] feel pain under my left ear, and [I] want to vomit, and the headache was persistent, [I] used to it till [I] went to the hospital and [I] didn't understand what the sound was. It was like that regularly". P^{SA10}

According to eight participants, although their tinnitus persisted, it was not as severe as during their initial attack. For instance, one participant mentioned that their tinnitus remained but gradually improved as they got older.

"A long time ago, it used to be continuous, but the sounds started disappearing with age… once in a week". P^{SA1}

"Tinnitus is still there, and it is less severe than before" P^{SA10}.

For some participants the nature of sound they were hearing changed over time.

"Now [I] don't hear any drum sound but different sound like blowing in the air". P^{SA8}

"It used to be like whisper, very light, but after COVID vaccine, it is like air conditioner". P^{SA7}

II. Tinnitus impact

Participants described the emotional impact of tinnitus and the overall impact on their quality of life including its effect on sleep, work and family time. They discussed how tinnitus often led to avoidance behaviours and isolation. The discussion also explored factors that influenced tinnitus such as triggers that increased or decreased its severity. Participants also

shared the coping strategies they developed over time to manage their tinnitus. Major subthemes were 'Factors affecting tinnitus', Emotional impact of tinnitus, 'Impact of tinnitus on quality of life' and 'Coping strategies.

Factors affecting tinnitus included overall tinnitus triggers, aggravators and relieving factors. Some participants mentioned that noise and work aggravated their tinnitus, while others were unable to identify specific factors that caused their tinnitus to worsen. The study participants mentioned different types of aggravating noise they had encountered. One participant characterised this as the sounds produced by children, while another participant defined it as the sounds emanating from their family members. This noise was commonly known as household noise.

"If I got angry. [I] feel that the sound increases if [I am] tired at work or [I am] taking care of the children". P^{SA3}

"Honestly, sometimes the sounds come in the evening after shift... possibly in the evening, sometimes after shift with no specific time". P^{SA1}

"If there is a noise, my tinnitus will increase. It is very annoying". P^{SA10}

"When [I] hear the tinnitus, [I] realise that [I] spent too much time using the mobile phone (...)". P^{SA13}

The first participant who mentioned noise as an aggravating factor had been deaf since birth and did not wear hearing aids. However, no further details were provided regarding the specific type of noise she was referring to, but it was assumed as coming from the home as she later said that she tended to isolate herself in her room away from her family.

"If there is a noise, my tinnitus will increase. It is very annoying". P^{SA10}

The second participant, who experienced an increase in tinnitus due to noise, identified work as a contributing factor to her tinnitus.

"My tinnitus increases when I am tired from work, or I am taking care of my children". P^{SA3}

Two people reported that hearing aids alleviated their tinnitus. One participant mentioned that their tinnitus would be less clear, if they were relaxing.

"She hears the sound when there is noise. If she took off the hearing aid, the sound would go away". P^{SA8}

"(...) it goes away sometimes when I wear the hearing aid". P^{SA3}

Emotional impact: Within this subtheme, the personal and emotional consequences of tinnitus were explored by three participants. One individual characterised their experience as a sense of cruelty, while another articulated the emotional burden of feeling alone in their pain, as if they were the sole person experiencing it. The third participant acknowledged that tinnitus had an impact on them but did not elaborate further. Notably, the remaining participants did not mention any emotional effects related to tinnitus and viewed it as something they could manage.

"Tinnitus takes all my focus; I can't do anything. All my focus is shifted to stop the tinnitus. I have to stop everything, then I feel like a feeling of cruelty". P^{SA1}

"Yes, it affects my life. Because [I] hear it on my own, not my friends. The sound (tinnitus) makes me tired and annoys me". P^{SA10}

Impact of tinnitus on quality of life: This subtheme examined the diverse impacts of tinnitus on different aspects of individuals' lives, including sleep, family time, work and the tendency to withdraw from social interactions. Sleep was not affected by tinnitus in the majority of the

participants. One participant stated his sleep was disturbed but that it was not due to tinnitus. Three participants attributed their sleep disturbance to tinnitus.

When participants were questioned about the impact of tinnitus on their work, nine individuals claimed that it did not interfere with their work or daily routine. However, four participants mentioned that if they experienced tinnitus while at work, it would affect them in different ways. One participant, a supervisor at a university, stated:

"Work overload can trigger my tinnitus". P^{SA3}

When asked if the tinnitus affected time with family, two participants stated that it did.

"*Tinnitus affects my time I spend with my family because of their loud voices. Loud noises can trigger my tinnitus".* P^{SA10}

"Yes, being with my family can trigger my tinnitus as the noise from the children are very loud". P^{SA3}

The included sample did not express a desire to become isolated. Only one participant expressed a desire to be avoided when their tinnitus occurred.

"I prefer staying alone, the more I searched for calmness in my room, the more I prefer to be alone. All my family can hear and talk except me, and this makes me annoyed". P^{SA10}

Coping strategies: Three participants reported different ways they habituated to their tinnitus sounds that worked very well for them. Keywords such as adapting to it, getting used to it, ignoring it, were deemed markers for habituation. One participant reported putting all his attention on the sound until it stopped.

"I focus on the sound for a while, the whole time until the sound goes away. It means that whenever there is a sound, I should focus on it". P^{SA1}

Two participants stated that they would stop whatever they are doing until their tinnitus fades.

"If the tinnitus was there, [I] will stop working until the sound disappeared so usually, [I] will take a break". P^{SA2}

The remaining participants indicated that they did not have any known remedies for their tinnitus and maintained the belief that there is no cure. One participant expressed a preference for being in a room with background noise when experiencing a tinnitus attack.

"There is nothing [I] do to remove it. It goes by its own way. [I] sit down and listen to the radio although [I] don't understand what is said". P^{SA12}

One participant, who did not have any known coping strategies, would opt to isolate herself in a quiet place when experiencing a tinnitus attack.

"Once [I] heard the tinnitus sound, [I] don't complain in front of people, [I] just isolate myself. It will go by itself". P^{SA10}

III.Healthcare provision to treat tinnitus

This theme addressed whether participants initially sought medical advice. Subtheme 1 (help seeking) concerns whether participants had sought help for tinnitus and if it was beneficial or not. Subtheme 2 (negative experience to healthcare providers) describes negative experiences which hindered participants from requesting more management or seeking help. Subtheme 3 (received support) describes support received by participants in managing their tinnitus, whether through specialised tinnitus groups or the support of their families. Subtheme 4 (future need on tinnitus management and research) describes participant perspectives that they believed would be valuable information for researchers in the field of tinnitus management and research.

Help seeking: Seven participants sought medical attention either during their first tinnitus attack or at least once in their lives. They all arrived at the same conclusion that either everything was fine or that there was no treatment available.

"I was admitted to hospital for a whole week, but nobody knew what the reason behind the Tinnitus was". P^{SA1}

"[I] went to the hospital, and they told me that there was no solution to my problem. There was no cure. In the hospital, they said that everything was fine. Everything was ok". P^{SA2}

One participant mentioned that she used medication to treat her tinnitus, although she could not remember the specific name of the medication.

"I was taking medications to treat the tinnitus". P^{SA7}

Negative experiences with healthcare providers: The responses from participants were variable as some reported negative experience, including communication difficulties and healthcare providers ignoring their tinnitus and concentrating solely on their hearing loss. One participant shared a negative experience regarding his initial diagnosis of tinnitus. He experienced sudden hearing loss and tinnitus and was admitted for a week to determine the cause of his hearing loss. However, no one discussed his tinnitus with him, and he mentioned that if someone were to suggest visiting the hospital, he would refuse:

"If someone told me I have to go to hospital, I will run away". P^{SA1}

Communication was a huge problem for one participant who had several attacks of severe tinnitus. As there was a communication barrier and healthcare providers did not try to assure, they were involved in the conversation and their treatment, they had to rely on their mother to explain what was going on.

"[I] didn't know the reason for it (tinnitus), but [I] was going to the hospital, and [I] wasn't understanding what they were saying, and they made me stay in the hospital many times. (...) Nothing, [I] went to the hospital, but [I] didn't understand what they were talking about. My mother was with [me], and she could explain to [me] what they were talking and maybe [I] was taking medications to decrease the tinnitus". P^{SA10}

Receiving support: None of the participants received any support or guidance in managing their tinnitus. When asked about receiving help from family or friends, all participants stated that they did not receive any support.

"I deal with it with my own". P^{SA1}

Future need for management and research: Participants shared their views on what they would like from future management and research. In terms of treatment, most participants had no opinion and used terms such as *"useless"*, or *"no cure to our condition"*. They have acknowledged that there is currently no cure for their tinnitus, and they were not inclined to actively seek a solution. Their perspective on this issue was pessimistic towards healthcare providers. Two participants stated they would like their tinnitus to stop permanently and for there to be a new medication for this.

"I used to go to for my hearing loss and tinnitus, but it was useless" P^{SA1}

"[I] wish you make a medicine for the deaf people in the future". P^{SA8}

"[I] don't think there is a cure for our condition". P^{SA4}

4.3.3 Mixed methods findings

Participants in this study were deaf from birth and used Saudi Arabian Sign Language, with one exception who experienced hearing loss at age 10. All participants reported tinnitus onset in childhood or early adulthood. Quantitative data from the Arabic THI suggested a predominantly mild impact, with only two participants indicating moderate to severe effects. However, qualitative data gathered through interviews revealed a more complex picture. The interviews uncovered significant variability in tinnitus impact among participants, often exposing effects that were not apparent from the questionnaire responses alone. Notably, some participants encountered difficulties completing the THI, raising questions about its appropriateness for assessing tinnitus impact in this specific population. This discrepancy between quantitative scores and qualitative insights highlights the value of methodological triangulation in capturing the full spectrum of tinnitus experiences in deaf sign language users. The combination of methods provided a more comprehensive understanding of tinnitus impact, revealing nuances that might have been missed by relying solely on standardised questionnaires or interviews alone.

4.4 Discussion

The research aim was to explore the lived tinnitus experience in deaf and severe-profound hearing-impaired SA adults. Based on that, a concurrent mixed method approach was used to validate each other.

4.4.1 Tinnitus severity and impact

The findings from the Arabic THI suggest that more than half of participants reported only mild tinnitus handicap, with no one indicating a catastrophic impact. This raises concerns about the THI's ability to fully capture the true effects of tinnitus, particularly in populations like the deaf community. The relationship between tinnitus and deafness, especially in those

who are pre-lingually deaf, is a subject of ongoing debate, as individuals in this group rarely report tinnitus (Eggermont & Kral, 2016).Furthermore, the validity of the THI for this population is questioned, as some participants felt certain questions were irrelevant or poorly designed for their experiences. In Saudi Arabia, where Saudi Arabian Sign Language (SASL), a language distinct from spoken Arabic, is used, communication challenges are heightened (Alofi et al., 2019; Altamimi & Alsager, 2023). SASL has its own grammar and syntax, and its word sign language organization follows a Subject-Verb-Object (SVO) structure similar to other worldwide sign language. However, SASL remains underrecognized in Saudi Arabia, with a need for more linguistic studies to explore its argument structure and word order (Altamimi & Alsager, 2023). Many deaf individuals face language deprivation, especially if they grow up in non-signing families, leading to cognitive and social difficulties (Alofi et al., 2019). Moreover, Deaf students often encounter poor educational quality, with limited sign language instruction, and face challenges when transitioning to mainstream schools. Ongoing challenges include linguistic deprivation, inadequate early intervention, and negative societal attitudes toward SASL, highlighting the need for improved education, support systems, and awareness of Deaf culture and SASL in Saudi Arabia (Alofi et al., 2019).

4.4.2 Tinnitus-associated comorbidities

Participants in this study showed variable levels of depression, anxiety, and stress, a commonly observed pattern in patients with tinnitus, as documented in previous studies (Beukes et al., 2021; Godere, 2022; Zhang et al., 2023). The mean score on the DASS-21 Depression (DASS-D) scale was 7.2 (SD = 9.2), indicating no depression for most participants. The findings from this study regarding depression levels in tinnitus patients present an intriguing contrast to some existing literature, particularly Zhang et al.'s (2023)

study. While our results align with the general observation of variable psychological symptoms in tinnitus patients, they diverge in terms of depression prevalence and severity.

The majority of participants (10 out of 13) in this study fell into the "no depression" category, with a mean DASS-21 Depression (DASS-D) score of 7.2 (SD = 9.2). This is notably lower than the levels of depression often associated with chronic tinnitus in previous research. Zhang et al. (2023), using the Hospital Anxiety and Depression Scale (HADS), concluded that chronic tinnitus is frequently accompanied by depression. However, our findings suggest a potentially different pattern. Several factors could contribute to this discrepancy including sample characteristics. Our small sample size (n=13) may not be fully representative of the broader tinnitus population. The specific demographics, tinnitus duration, and severity in our cohort could influence the observed depression levels. Also, Temporal factors as the timing of our study, potentially coinciding with external events or seasonal variations, might have influenced participants' psychological states.

It's worth noting that while most of our participants showed no depression, we did observe cases of moderate (n=2) and extremely severe (n=1) depression. This variability aligns with broader findings in tinnitus research, such as those reported by Beukes et al. (2021) and Goderie (2022), emphasising the heterogeneous nature of psychological comorbidities in tinnitus patients.

These results underscore the importance of individualised assessment in tinnitus management. While our findings suggest a lower prevalence of depression than some previous studies, they reinforce the need for comprehensive psychological screening in tinnitus patients, as recommended by current management guidelines (NICE, 2020).

Scores on the DASS-21 Anxiety (DASS-A) scale were more variable. The mean score was 7.7 (SD = 9.7), indicating a range between no anxiety and mild anxiety. Six participants

scored in the "no anxiety" category (scores between 0 and 7), three had mild anxiety (scores between 8 and 9), two had moderate anxiety (scores between 10 and 14), and two had extremely severe anxiety (scores over 20). This variability aligns with Goderie (2022) findings using the Four-Dimensional Symptom Questionnaire (4DSQ), which reported higher anxiety levels in individuals with new-onset or annoying tinnitus. Beukes et al. (2021) also emphasized that anxiety is a strong predictor of tinnitus severity, alongside insomnia and hearing disability.

Interestingly, this study found a higher prevalence of anxiety than depression among participants, despite their chronic tinnitus complaints. This contrasts with Zhang et al.'s (2023) findings, where chronic tinnitus was more strongly associated with depression. One possible explanation is that this study was conducted during the COVID-19 pandemic, a period marked by heightened anxieties related to health and well-being (Liyanage et al., 2021). External factors like the pandemic may have amplified participants' anxiety levels beyond what is typically observed in chronic tinnitus populations.

The mean score on the DASS-21 Stress (DASS-S) scale was 10 (SD = 10.2), indicating no stress for most participants. Ten participants fell into the "no stress" category, one had moderate stress (score between 19 and 25), and two had severe stress (scores between 26 and 33). These findings suggest that stress levels were generally lower than levels of depression and anxiety in this cohort.

As highlighted by NICE guidelines for tinnitus management (NICE, 2020), screening for comorbidities such as anxiety, depression, and stress is crucial to ensure timely intervention. The current study reinforces the importance of addressing psychological comorbidities in tinnitus patients, particularly during times of heightened external stressors like a global pandemic.

4.4.3 Interviews key findings

As Saudi participants shared their first encounter with tinnitus, it was clear that most of them had an onset of tinnitus as early as 9-10 years old and it was unclear in the start. This finding challenges the belief that deaf individuals may not experience tinnitus due to a lack of auditory experience. Contrary to common belief, tinnitus is not only experienced by individuals with acquired hearing loss but can also occur in those who are deaf from birth. A notable finding was that the participants were able to accurately describe their tinnitus sound, which were similar to those experienced by individuals with acquired hearing loss. For instance, participants frequently described buzzing or tonal sounds or sudden loud sounds. This is exemplified by the case of a profoundly deaf individual with Waardenburg syndrome, who reported experiencing tinnitus all his life (Wheeler & Hopwood, 2015).

For most participants tinnitus severity changed over time. Tinnitus natural history is often discussed in the literature (Dawes et al., 2020; Phillips et al., 2018) as tinnitus severity might improve or worsen over the years. With respect to factors that can trigger or alleviate tinnitus, exposure to loud noises was a trigger and a source of relief for their tinnitus in some participants. Household noise in the form of noise coming from family members or children screaming acted as a trigger.

Interestingly, some participants found relief when sitting in a place with background noise. This finding is consistent with a study by Colagrosso (2018), where some subjects reported that benefit from sound enrichment strategies such as listening to the radio can alleviate tinnitus attacks and for some their tinnitus was exacerbated by loud noises (Colagrosso et al., 2019). While noise is a known risk factor for tinnitus development, this study does not provide an explanation for how individuals who are deaf or severe-profoundly hearing-impaired perceive sound.

Individual factors such as stress, fatigue, sleep disturbances and auditory strain can have a dual effect (Colagrosso et al., 2019). They can either worsen existing tinnitus or tinnitus itself can lead to stress, fatigue and sleep disturbances.

One participant experienced a new form of tinnitus after receiving the COVID-19 vaccine. Since the pandemic and the introduction of various new vaccines, numerous patients have reported new cases of tinnitus, as well as other related symptoms like hearing loss and vertigo. Studies have investigated the occurrence of these new auditory complaints, but the rate was relatively low (Degen et al., 2022; Lin & Selleck, 2023; Pisani et al., 2022). Further evaluation is necessary to determine the benefits of vaccinations in controlling the pandemic and addressing these issues.

The emotional impact of tinnitus was found to be minimal for most participants in the study. Only three participants reported experiencing some emotional impact, such as feelings of confusion or frustration. One participant described their experience as cruel, stating that they felt harshness and difficulty whenever their tinnitus occurred. The cognitive function of humans, particularly learning, attention, and memory, can be significantly affected by emotions (Tyng et al., 2017). This could potentially explain why certain individuals are more able to manage tinnitus than others as they were able to learn and adapt coping mechanisms. Additionally, psychological disorders like depression and anxiety have been linked to impairments in learning and memory.

Tinnitus has a significant effect on the wellbeing of individuals who are severely affected by it. This includes difficulties with sleep, missing work, distancing themselves from family gatherings, and ultimately seeking isolation and avoidance. According to the study's findings, most of participants reported little impact on their sleep, work, and ability to participate in family gatherings.

Participants reported coping strategies to manage their tinnitus, which they had developed over time, with habituation being the most prominent. They often expressed their habituation mechanism by using phrases like "I adapt to the sound" or "I am used to it".

Some participants used hearing aids which were viewed as either reducing the intensity of the tinnitus or exacerbating it. According to Wallhäusser-Franke et al. (2012), individuals with less distress from tinnitus experienced greater benefits from hearing aids, while those with higher distress experienced an increase in tinnitus loudness when using hearing aids (Wallhäusser-Franke et al., 2012). In terms of seeking help, over half of the sample had not sought treatment for their tinnitus. They viewed it as useless and not beneficial. Communication was also a significant challenge when they sought assistance. This finding aligns with the research conducted by Beukes et al. (2018), who also found that individuals who experienced tinnitus at a younger age were better able to handle it. However, the study also reported lower hearing ability among the participants, which cannot fully explain this phenomenon in the study sample (deaf). In the current study participants deafness hindered them asking for help along with the presence of communication barriers associated with their hearing loss. This aligns with the research showing adults with more severe degrees of hearing loss are less likely to seek help (Wells et al., 2020).

Some participants who had sought treatment for their tinnitus experienced highly unfavourable encounters with healthcare providers, resulting in heightened emotional impact, increased depression, and a loss of faith in the healthcare system. Support was clearly not provided to these participants. This lack of engagement and involvement of participants in tinnitus healthcare conversations may explain why, when asked, none of the participants in this study expressed any opinion on the future need for tinnitus research and management.

4.5 Conclusion

The present study explored the lived experience of tinnitus in deaf and severe-profound hearing-impaired adults in Saudi Arabia using a concurrent mixed method approach, providing a comprehensive view of both symptom impact and coping mechanisms. Notably, most participants reported only a mild tinnitus handicap on the Arabic THI, with none experiencing catastrophic effects—a finding that raises concerns regarding the sensitivity and appropriateness of this questionnaire for deaf populations. Emerging literature on the Arabic THI confirms its general validity and reliability for tinnitus assessment but also highlights the need for careful cultural and linguistic adaptation when applied to unique groups such as the Deaf community.

The complexity of tinnitus in this group is further compounded by sociolinguistic challenges, including language deprivation and limited recognition of Saudi Arabian Sign Language, which in turn affect healthcare access and communication outcomes. Psychological comorbidity screening in this study revealed generally low levels of depression, anxiety, and stress, although some variability exists. This pattern underscores the heterogeneous nature of psychological responses to tinnitus and suggests that external factors—such as the ongoing pandemic—can elevate anxiety levels unexpectedly.

Qualitative interviews revealed that tinnitus onset often occurred early in life and was described with much of the same sensory detail as seen in those with acquired hearing loss. While coping strategies, particularly habituation, were prevalent and often effective, communication barriers and limited access to tailored healthcare interventions hindered treatment-seeking behaviour and satisfaction. Hearing aids delivered mixed results, and unfavourable healthcare encounters occasionally worsened emotional distress.

In summary, this study demonstrates that while deaf and severely hearing-impaired adults in Saudi Arabia may experience milder tinnitus symptoms on average, significant obstacles

remain in accurately assessing, treating, and supporting their unique needs. There is a critical need for culturally sensitive and communication-accessible clinical tools, broader public awareness, and more inclusive support systems to enable individualized care and improve wellbeing in this underserved population.

Chapter 5 The lived experience of tinnitus in deaf and severely-to-profoundly hearing-impaired adults in the United Kingdom.

5.1 Introduction

Tinnitus affects approximately 10% to 15% of the adult population in the United Kingdom (Davis and El Rafaie, 2000). Additionally, the occurrence of tinnitus tends to increase with age, with the highest rates observed in individuals aged 60-69 (Baguley et al., 2013).

As reviewed in Chapter 1, the most common risk factors for tinnitus development including hearing loss, ageing and head injury. It is noted that previous tinnitus studies have not specifically targeted D/deaf or severe-profound hearing-impaired adults, even though they included individuals with different levels of hearing loss. Consequently, there is a dearth of information regarding the specific impact of tinnitus on this population, leading to a lack of guidelines for effectively managing tinnitus in D/deaf and severely profound hearing-impaired adults. In Chapter 4, the lived experience of a sample of adults in Saudi Arabia who were deaf, and experience tinnitus was examined. Most of the sample were pre-lingually deaf and communicated primarily using sign-language and lip reading. For them, tinnitus severity was assessed as low using the THI, but various issues were identified through interview that illustrated a negative effect, including effects on work, on concentration, and negative experiences of healthcare.

In the UK, tinnitus care is guided by NICE (2020) and the British Society of Audiology (2021), and most treatments require moderate access to sound (i.e. sound therapies, talking therapies). While studies have been conducted on the impact of tinnitus on individuals in UK populations (e.g., Watts et al., 2018) studies specifically examining the lived experience of those who are Deaf or have severe-to-profound hearing loss are still lacking.

5.1.1 Aim

The aim of this mixed method study was to investigate the lived tinnitus experience in D/deaf and severe-profound hearing-impaired adults in the United Kingdom.

5.1.2 Objectives

The objectives were:

5. To investigate tinnitus severity using the Tinnitus Handicap Inventory questionnaires.
6. To investigate presence of tinnitus associated comorbidities using the Depression, Anxiety and Stress Scale.
7. To investigate tinnitus lived experience through semi-structured interviews.
8. Finally, to triangulate the study results.

5.2 Methods

5.2.1 Quantitative data

Quantitative data consisted of basic demographic surveys to explore participants' age, cause of hearing loss and type and finally preferred mode of communication followed by tinnitus impact and comorbidities questionnaires. The THI was selected to evaluate the severity of tinnitus in the participants included in the study (Newman et al., 1996). The THI is a clinical tool consisting of 25 items that assess the impact of tinnitus on various aspects of daily life. Participants were asked to respond on a three-point scale, with "yes" receiving 4 points, "sometimes" receiving 2 points, and "no" receiving 0 points. Total score was calculated by summing the scores from all items across all subscales, with higher scores indicating a greater level of tinnitus impact. It is classified into five categories denoting handicap severity:

no handicap (0-16), mild handicap (18-36), moderate handicap (38-56), severe handicap (58-76) or catastrophic handicap (78-100).

The Depression, Anxiety and Stress Scale 21 (DASS-21) was chosen to assess the severity of symptoms in the three categories experienced within the previous week (Lovibond & Lovibond, 1995). There are 21 items (7 items in each subscale), and the scores are multiplied by two to obtain the full-scale scores. Total scores are calculated by summing the scores of the 14 items in each subscale.

5.2.2 Qualitative data

The qualitative part of this study consisted of an interview guide that covers three main aspects related to tinnitus as described in Chapter 3. Data were collected remotely except for one participant who had a face-to face interview. Only one participant required a British Sign Language (BSL) interpreter, which was provided to her.

5.3 Results

5.3.1 Quantitative findings

Thirteen participants were included (seven women, six men), and the average age of participants was 62.85 years (SD=45.9, range 33-82). Summary demographic information can be found in Table 5.1. In respect to the onset of hearing loss most participants experienced hearing loss later in life, except for two cases (P^{UK9}, P^{UK13}). Participants gave a variety of answers when asked about the cause of their hearing loss. In two cases, the cause was multifactorial (P^{UK7}& P^{UK10}). For example, P^{UK7} had unilateral hearing loss due to a head injury from a fall and later developed hearing loss in the other ear. P^{UK10} had otosclerosis and required multiple surgeries but was later diagnosed with a severe form of Meniere's disease and needed treatment with ototoxic medication. Six participants P^{UK3}, P^{UK8}, P^{UK9}, P^{UK11}, P^{UK12}, P^{UK13} had genetic hearing loss, with two cases having it since birth (P^{UK9}, P^{UK13}) or early

childhood, and the others developing it later in life (P^{UK3}, P^{UK8}, P^{UK11}, P^{UK12}). Three participants (P^{UK1}, P^{UK2}, P^{UK5}) attributed their hearing loss to childhood infections, including measles and scarlet fever, which gradually impacted their hearing and affected their lives. Some participants also had exposure to loud noise, which may have contributed to their condition. Finally, two cases had no known cause for their hearing loss (P^{UK4}, P^{UK6}). Regarding the use of assistive devices, participants were asked about their usage. Among them, seven participants reported using cochlear implants, four participants reported using hearing aids, and two participants reported using both (a cochlear implant in one ear and a hearing aid in the other ear). Most participants were able to communicate orally, with some relying on lip reading. Attending lip reading classes proved to be highly beneficial for them.

Table 5.1 Demographic summary of included UK participants

ID number	Age	Gender	Ethnicity	Onset of HL (age or life stage)/ type of HL	Cause of HL	Mode of communication	Use of assistive devices
P^{UK1}	82	Male	British English	Gradual loss at the age of 32/ post-lingual	Complication of childhood infection	Oral	Left cochlear implant
P^{UK2}	58	Female	British English	Deaf since birth in the left ear while right gradual loss as teenager/ post-lingual	Complication of childhood infection	Oral+ lip reader	Right cochlear implant
P^{UK3}	78	Female	British English	Gradual loss at the age of 42/ post-lingual	Genetics	Oral	Right cochlear implant
P^{UK4}	74	Male	British English	Gradual loss at the age of 18 years/ post-lingual	Unknown	Oral	Hearing aid
P^{UK5}	69	Male	British English	Gradual loss at early teenage/ post-lingual	Complication of childhood infection	Oral	Left cochlear implant
P^{UK6}	77	Male	British Indian	Gradual loss later in life/ post-lingual	Unknown	Oral	Right cochlear implant
P^{UK7}	72	Male	British English	Gradual loss around the age of 30 and 60/ post-lingual	Multiple factors	Oral	Left cochlear implant
P^{UK8}	50	Female	British English	Gradual loss at the age of 29 years/ post lingual	Genetics	Oral	Right cochlear implant & left hearing aid
P^{UK9}	33	Female	British English	Since birth/ pre-lingual	Genetics	Sign language	Cochlear implant

P^{UK10}	73	Male	British English	Gradual loss at the age of 30/ post-lingual	Multiple factors	Oral	Left cochlear implant & right hearing aid
P^{UK11}	51	Female	British English	Gradual loss around the 20-30 (post-lingual)	Genetics	Oral	Hearing aid
P^{UK12}	57	Female	British English	Gradual loss around the 20-30 (post-lingual)	Genetics	Lip-reader	Hearing aid
P^{UK13}	43	Female	British English	Gradual loss at early childhood (5 years) (post-lingual)	Genetics	Oral	Hearing aid

The average THI score of all participants 46.2 (SD=25.4) equating an average moderate tinnitus handicap. However, only three of the 13 individual participants had a moderate tinnitus handicap (scoring 38-56 points). Six participants had mild tinnitus handicap (18-36 points), one had severe tinnitus handicap (58-76 points), and three scored 78-100 indicating catastrophic tinnitus handicap. No participant was classified as having slight or no tinnitus handicap.

Scores on the DASS were equally variable. The average score on DASS-D (symptoms related to depression) was 9.6 (SD=11.6) which borders normal to mild symptoms of depression. Most participants fell into these categories. However, two participants scored over 20, indicating severe symptoms of depression, and one participant scored 34 indicating extremely severe symptoms of depression.

In terms of anxiety (DASS-A), the average score was 7.8 (SD=10.9), the average score bordering normal and mild symptoms of anxiety. However, nine participants had normal levels of symptoms of anxiety, and none fell into the mild category. Two participants had moderate symptoms of anxiety (scores 10-14), and two had extremely severe symptoms of anxiety (scores >20).

Symptoms of stress were similarly distributed. The average score on the DASS-S was 11.2 (SD=8.6), with the average being interpreted as normal levels of stress (score less than 15). Ten of the 13 participants were categorised as having normal levels of symptoms of stress. One participant had mild (score 15-18), one participant had moderate (score 19-25), and one participant had severe symptoms of stress (score 26-33). No participants were classified as having extremely severe stress.

5.3.2 Qualitative finding

Three overarching themes were derived from the data. These were Characteristics of tinnitus, Tinnitus impact, and Healthcare provision to treat tinnitus.

I. Characteristics of tinnitus

Participants talked about the onset of their tinnitus, tinnitus sound characteristics, changes in tinnitus over time, and causes of tinnitus. They reflected on the moment they first became aware of tinnitus, describing its characteristics and any accompanying symptoms. Some participants also spoke about individuals who provided support in dealing with the condition and discussed the natural progression of their tinnitus.

While some participants remembered a specific incident or moment when they first experienced tinnitus, others felt that it had always been present in their lives. Interestingly, one participant even considered tinnitus to be a normal sound that everyone hears, including those with normal hearing.

"I remember reading an article in the newspaper when I was fifteen and it was a double page spread on tinnitus, they had just named this condition as tinnitus and I said to my mum do you have this and she said no, I thought it was normal, so I think I always had it". P^{UK2}

Tinnitus was constantly present for four participants. However, one of those participants noted that while their tinnitus had always been present, its characteristics suddenly changed.

"I am unable to remember the exact first time that I heard tinnitus but there was always random sound in my early childhood. But it really affected me at age of seventeen years. I woke up with roaring buzzing in my ears". P^{UK13}

On the other hand, some participants stated that their tinnitus onset was concomitant with an injury which led to their hearing loss. For example, one participant had a head injury following a fall which caused unilateral hearing loss and sudden tinnitus.

"I got tinnitus the same time I had my head injury in the right ear". P^{UK7}

One participant stated that their tinnitus was due to a bilateral stapedectomy, and another presumed their tinnitus was due to exposure to loud music.

"I think when I was eighteen following pop concerts. I went to hear it ringing in my ears for days and I never knew weather that was normal or not or weather this was me". P^{UK11}

The remaining participants developed tinnitus in their mid-30s or 40s, which coincided with a gradual decline in their hearing.

"It was no long after I become deaf, and it started gradually, and I kept hearing the noises but couldn't understand it. At the start I didn't complain because it wasn't loud". P^{UK4}

When participants were asked if they could describe the sound quality of their tinnitus, answers were variable and ranged between one single sound to multiple sounds.

"The tinnitus just sounded like a traffic in the car distance". P^{UK1}

"*Multiple sound, always changing such as a lorry reversing, the insistent beep-beep. Also, a rushing sound like being underwater".* P^{UK13}

Participants in this study reported varying sound characteristics of their tinnitus, but the loudness was consistently identified as the most bothersome feature, and stress was found to be the primary factor influencing the loudness of participants' tinnitus.

"Many sound the varies according to whatever I was stressed". P[UK4]

"A loud buzzing noise that become louder when I am stressed". P[UK7]

"I am not religious person, but it is like playing tunes from hymns, quite depressive tune and very loud". P[UK10]

Participants' responses regarding the location of their tinnitus varied. Three participants noted that their tinnitus shifted to be localised at the site of their cochlear implant.

"*It used to be both side, but now more in the left side where my CI* is". P[UK1]

"*It was initially in the left side but after CI in my right ear, the tinnitus become in my right ear".* P[UK3]

Other participants experienced either unilateral or bilateral tinnitus, with one participant unable to determine the location and another reporting it as being in their head. As tinnitus is an internal sound that can only be heard by the individual experiencing it, some participants sought confirmation or assistance in identifying and verifying whether a corresponding external sound was present. Only one participant in the study required validation from her family. The individual in question has been deaf from birth and was only able to perceive loud sounds.

"I said to my sister: the phone ringing, pick it up. But there was no phone ringing. I was sure there was a phone ringing because that's what I could hear. So, I think that was the first indicator of it. I was in bed, and I thought I could hear a phone ringing. I had no implant at

that time. I had no hearing aids. And then I started hearing that every time I went to bed in the evening". P^{UK9}

During the interviews, participants shared their beliefs about the cause of their tinnitus. Some participants believed that their tinnitus was related to their hearing loss. Others speculated about changes in their body chemistry or exposure to loud noise as possible causes. Some participants admitted that they were unsure of the exact reason for their tinnitus, despite considering various factors. Interestingly, one participant attributed the cause of her tinnitus to her deafness, as she believed that her inability to hear external sounds made it difficult to mask or alleviate the tinnitus.

"I really don't know but may be because I am profoundly deaf. It has worsened because there is no real sound to offset it". P^{UK13}

Most participants described tinnitus as a constant sound that is present all day, in terms of its duration and occurrence. For others it was intermittent.

"It can last few minutes and can last for hours". P^{UK9}

"It is persistent". P^{UK10}

One participant recognised that their tinnitus was constantly present but could be concealed when using their cochlear implant.

"Cochlear implant let you hear external noises, so you don't notice your tinnitus". P^{UK7}

One participant reported experiencing headaches associated with tinnitus, especially during her first attack.

"*There were always random sounds in my childhood, but I didn't have the means of processing them for what they were. The first time I had a but which truly affected me was at age 17years. I simply woke up with a roaring buzzing in my ears. I spent most of that day in bed with a headache. This lasted for several days".* P^{UK13}

Participants reported that their experience of tinnitus evolved over time, either naturally (unknown cause) or because of cochlear implantation. Three participants reported that, following implant surgery, the loudness of tinnitus was high but returned to their normal level.

"I think general sounds are much louder. It is not just the tinnitus sound. It is everything is louder. So, like I said I could hear a clock ticking, that clock ticking will sound much louder. When I got this attack of tinnitus". P^{UK1}

The most crucial element that participants reported in relation to their tinnitus outcome was awareness of tinnitus.

"Tinnitus is always there as long I am not aware of it. Now I am aware of my tinnitus sound because I am talking about it". P^{UK8}

II. Tinnitus impact

Participants discussed the emotional and functional impact that tinnitus had on them. They identified factors affecting their tinnitus. They also discussed they ways that they coped with

their tinnitus. Major subthemes were ‘Factors affecting tinnitus’, Emotional impact of tinnitus, ‘Impact of tinnitus on quality of life’ and ‘Coping strategies.

Factors affecting tinnitus: Participants emphasised that there were several factors that can significantly exacerbate their tinnitus, and issues related to noise were commonly discussed. These factors either intensified existing tinnitus episodes or served as triggers for new ones. For instance, noise could originate from various sources, ranging from loud environments such as workplaces or family gatherings to undergoing hearing assessment tests where a certain beep can trigger the noise.

“My tinnitus goes most of the time in the backgrounds, I am not aware of it unless something spiking like loud noise”. P^{UK3}

“The key here is getting away from the challenge of noise. It is the most frustrating thing, and I have to sort it myself”. P^{UK12}

“[I] go for an appointment, and they do the beeps, [I] come home and there is that irritating beep that [I] still going there, even though [I] got the implant off so that beeping noise is so annoying. [I] cannot rid of it. That keeping going for hours”. P^{UK9}

In addition to noise, one participant mentioned that focusing on their tinnitus could increase its volume. Another participant noted that concentrating on their tinnitus could amplify its intensity, aside from noise.

“Noise is more likely to exacerbate my tinnitus but thinking about it also make it louder” P^{UK13}

One participant noted that sitting in background noise can relieve his tinnitus whereas another participant reported that wearing hearing aids can relieve his tinnitus.

"Surprisingly, wearing my hearing aids can reduce my tinnitus". P^{UK4}

For some participants, tinnitus was less noticeable when resting while for others, focusing on something until they became unaware of tinnitus was what relieved it. Some participants expressed scepticism about finding relief from their tinnitus, but one participant shared that she was able to effectively manage her tinnitus during the COVID-19 mandated lockdown. This could be attributed to her working from home, a reduced workload and accompanying stress and fatigue, ultimately improving her tinnitus condition.

"There is nothing I guess can relieve my tinnitus although lockdown help me a little bit by staying at home and doing work remotely". P^{UK2}

Some participants also stated that they could pinpoint what triggered their tinnitus.

"I think there is a connection between when I had general anaesthetic when I was twenty-nine and when I had the implant because each time, I had a general anaesthetic the tinnitus has got worse". P^{UK2}

Some participants identified multiple triggers of tinnitus.

"Many things can trigger it such as Alcohol, stress, tiredness, illness so I have to live cautiously quite". P^{UK11}

Emotional impact of tinnitus: Some participants found it difficult to accept and cope with their tinnitus, while others believed they could effectively manage it. Reports varied greatly,

with some participants experiencing a significant impact and others feeling no impact of tinnitus on their emotional state at all. Certain individuals even considered tinnitus to be a fundamental part of their identity that they can deal with.

"Tinnitus has a massive impact on me. I cannot mask it because I cannot use equipment out there like white noise and sound maskers so the biggest impact it has on the quality of my life is. ...I am exhausted because my brain can't stop because of the sound in my head". P^{UK2}

"It did in the start, and I remember sitting in the bath crying…. because I thought Oh, what I am going to do? It was very invasive in the start, and it affected my mental health". P^{UK3}

Several participants initially faced challenges with tinnitus but eventually found ways to manage it. On the other hand, some participants chose to accept their condition, as they believed that struggling against it was pointless.

"No, no impact at all, I mean there is other things to care about it. Also, I am optimist and positive which I think this does help me". P^{UK1}

It was felt that acceptance is the ultimate outcome of the struggle with tinnitus, and it arises when one acknowledges that there is no way to avoid this condition and instead one chooses to embrace it as a natural part of life and personal beliefs.

"Well, it was causing me quite few problems and [I] had to sore readjust my thinking about because [I] realise it wasn't going to go away. And [I] and [I] am going to stuck with it for the rest of my life. So, [I] mentally accepted as part of me". P^{UK9}

"I accepted as part of my faith". P^{UK4}

"Tinnitus is part of me now but used to drive me crazy". P^{UK5}

Impact of tinnitus on quality of life: Effects of tinnitus on essential daily activities included negative impacts on sleep routines, performance at work, and quality time spent with family. Moreover, tinnitus led to individuals avoiding social interactions and isolating themselves. A significant number of participants with tinnitus experienced difficulties in both falling asleep and staying asleep due to the persistent ringing sound.

"Yes, if the tinnitus at night-time, [I] tried to wait for it for finish and [I] cannot sleep" P^{UK9}

"The tinnitus is always there so I cannot go to sleep quickly". P^{UK12}

Stress was also a factor reported to exacerbate tinnitus and further impact sleep. The constant presence of tinnitus caused stress and anxiety, creating a vicious cycle where stress worsened tinnitus, which in turn affected sleep. This cycle was considered particularly challenging to break, as stress can make it even harder to fall asleep or stay asleep.

"Well, tinnitus affects approximately half the nights. It is a vicious cycle that if I am stressed then my tinnitus will prevent me from sleep". P^{UK13}

For some individuals, tinnitus was loud and disruptive, making it challenging to fall asleep.

"It was disruptive like my sleep that I had to attending sleeping classes and take Melatonin" P^{UK2}

In addition to difficulty falling asleep, tinnitus caused some participants to wake up during the night.

"It wakes me up like three times because it is so noisy". P^{UK10}

In some cases, individuals with tinnitus had to wait for the ringing sound to fade before they could fall asleep. This waiting period was frustrating and time-consuming, further contributing to difficulties in getting adequate sleep.

"I have trouble getting off to sleep because there is noise in my head".

P^{UK11}

The impact of tinnitus on work performance was noteworthy as well. Persistent ringing or buzzing sounds were considered highly distracting, making it challenging to maintain focus on tasks. Consequently, productivity and efficiency declined. Moreover, tinnitus induced fatigue and irritability, further hindering concentration and motivation during the workday. In some cases, individuals felt the need to take breaks or make adjustments to their work environment to mitigate the effects of tinnitus on their job performance. Indeed, two participants mentioned that their tinnitus ultimately led to them retiring early. This highlights the severity of the impact that tinnitus can have on an individual's ability to work effectively.

"Affected because it is 24/7 but I distract myself although I am very exhausted". P^{UK2}

"It affected me until I have to retired". P^{UK4}

"I think it was once I realised that I was struggling in my job. And I was getting very, very tired. The temperatures and I would want to be quiet all the time. I want to come home and I would just exhausted headaches that sleep a lot and obviously actually temper and that's that saying I was erratic, but I felt myself being shorter tempered and having to take a breath because I was just exhausted. So, I have to retire". P^{UK12}

Tinnitus significantly impacted the participants' ability to fully enjoy meaningful moments with their family. It resulted in feelings of frustration and irritability, making it challenging to

fully engage and appreciate family time. It also influenced their choices regarding social gatherings.

"A bit, because [I] need to concentrate on one person and my implant off and [I] got tinnitus in the same time". P^{UK9}

"I prefer small gathering rather than big one". P^{UK12}

"I become resilient to attend any family event because of the noise". P^{UK4}

Exceptionally, one participant declined to stay in quiet spaces and instead preferred to always be with their family. Open communication about their tinnitus and its effects on their family time was considered beneficial by some individuals. This helped family members gain understanding and provide support to the affected person.

"Tinnitus rarely prevents me from doing anything I want except of it so bad then I have to cancel plans, but it is tiring thing to live with…so my family usually bear the brunt of this". P^{UK13}

"No, my family are very supportive, and I have regular friends". P^{UK3}

Tinnitus also magnified feelings of isolation and withdrawal from social engagements. The constant ringing sound was considered extremely distracting, impeding individuals from fully participating in conversations or activities. Consequently, frustration and embarrassment arose, prompting individuals to actively steer clear of social situations or to completely withdraw from social interactions.

Although the presence of deafness is often believed to be a potential cause of isolation due to communication difficulties, most participants in the study denied experiencing isolation or avoiding social interactions specifically because of their tinnitus. However, it is important to

acknowledge that the combination of deafness and tinnitus can potentially heighten the likelihood of feeling isolated. This was observed in several participants.

"I am not lonely person, nor I am isolated, but all deaf people are isolated". P^{UK2}

"Both deafness and tinnitus contribute to feeling isolated when they negatively affected impact my life". P^{UK13}

Some participants experienced tinnitus triggered by the fear of noise or stress, which ultimately resulted in social isolation.

"I rarely go out in big group because noisy environment can make my tinnitus worse". P^{UK12}

"Well, I think being deaf and having tinnitus made me more reclusive. So, I watch TV alone with subtitles because I don't want to interact with anybody". P^{UK11}

Coping strategies: Several participants demonstrated self-developed strategies for habituation or managing their tinnitus after enduring it for a prolonged duration. These coping mechanisms were only effective in certain circumstances.

"What work in day is not necessarily work at night. At day, I can distract myself while working". P^{UK2}

Distraction can be achieved by engaging in any kind of work, even playing a puzzle or gardening or doing something calming.

"[I] try and do something very different and calming. So, whether it's making a drink go to the loo just a five-minute walk, just to calm down then the tinnitus will reduce, and [I] can go back to whatever the thing was that [I] was doing". P^{UK9}

Coping strategies to reduce tinnitus can be facilitated by the presence or absence of assistive devices. One participant found relief from tinnitus by switching off his cochlear implant, while participant whose used hearing aids had varied experiences.

"When I take the cochlear implant off, the enhancement of the sound is off. But it doesn't stop the tinnitus". P^{UK1}

"When I go to bed and I turn off my CI, I can hear my tinnitus". P^{UK7}

"Hearing aids strangely enough help reducing it". P^{UK4}

"It doesn't matter whether I put a HA in or take it out. Tinnitus is still there. In fact, if I take the HA out it probably gets much worse". P^{UK10}

Many ignored tinnitus as their ultimate coping mechanism; however, this did not always work. One participant stated that she used loud noise such as watching TV at high volume or doing something that required loud noise as her coping mechanism.

"I do anything that require noise rather than sitting in silence. I also found screaming and shouting can help temporarily". P^{UK13}

III. Healthcare provision to treat tinnitus

This theme addressed whether participants initially sought medical advice. Subtheme 1 (help seeking) concerns whether participants had sought help for tinnitus and if it was beneficial or not. Subtheme 2 (negative experience to healthcare providers) describes negative experiences which hindered participants from requesting more management or seeking help. Subtheme 3 (received support) describes support received by participants in managing their tinnitus, whether through specialised tinnitus groups or the support of their families. Subtheme 4 (future need on tinnitus management and research) describes participant perspectives that

they believed would be valuable information for researchers in the field of tinnitus management and research.

Help seeking: Some participants actively pursued treatment options, while others believed that seeking assistance was unnecessary and that there were no viable solutions available. Several participants sought advice despite knowing that it may not be beneficial for their specific condition, such as in cases where masking techniques are not effective for individuals who are deaf.

"I asked but didn't do much help, but my GPs was helpful where he referred me to Psychiatrist". P^{UK4}

"I asked and they were very helpful but cannot find any strategies for my tinnitus", P^{UK5}

"Masking my tinnitus don't work in my condition". P^{UK6}

"I have spoken to my general practitioner and my audiologist over the years, but nobody has a constructive advice that actually work", P^{UK13}

For those who did not ask for medical help it was often justified by their ability to manage the condition themselves, or that tinnitus had never been a significant concern for them.

"Well, [I] can manage. It's annoying when it happens, but [I] find [I] can manage and do something different or put my implants on and then that stops it. So, [I] feel [I] can manage". P^{UK9}

"I never asked because I just assumed nothing can be done about my tinnitus, so I stopped talking about it". P^{UK11}

Negative experience with healthcare providers: Three participants had highly negative encounters while seeking assistance for tinnitus from healthcare providers. These experiences

stemmed from healthcare providers lacking comprehensive knowledge about tinnitus, resulting in a lack of understanding of how to effectively aid their patients.

"[I] am very disappointed from my general practitioner because they are uneducated enough and they don't know where to signpost people for support". P^{UK2}

Lack of understanding or recognition of the condition by doctors and audiologists can exacerbate frustration and depression in certain patients.

"It depresses me really because thy just say you have tinnitus, and you have to get with it". P^{UK3}

In cases where doctors and audiologists were not familiar with the condition, the management strategies provided were not considered effective for addressing this condition.

"*Some of the advice they give are unrealistic such as listening to white noise, and it will go way. Even when I was refereed to counselling clinic for tinnitus and she said she have no idea".* P^{UK13}

Received support: Support groups are a common occurrence for individuals with similar conditions to come together, share their experiences and seek solace. Few participants experiencing tinnitus were referred to local tinnitus support groups. Moreover, one participant expressed dissatisfaction with a particular support group that seemed to be more focused on individuals with normal hearing.

"So, [I] joined a tinnitus support group where [I] lived and [I] met up with the lady who used to run it and she said to be honest Case she said the level of the tinnitus you are experiencing we know there is nothing out there to support you, it's more for people with hearing that can benefit". P^{UK2}

The same participant pointed out a significant drawback of this support group, emphasising the potential harm of participants sharing negative thoughts that could have a detrimental impact on others.

"[I] found some platforms where there are some people similar to myself and they are all suicidal and so [I] stopped because that because it is not helping at all". P^{UK2}

Another participant found the support group to be beneficial, as it provided an opportunity for him to address individuals who shared similar experiences. Some participants received support from their family and friends, who may not have tinnitus themselves but showed empathy, understanding, and help.

"Although [I] live by myself, my family are very supportive. I also have regular friends". P^{UK3}

"[I]'ve got good friends, and my friends got tinnitus as well because the friends are all deaf. But now get off and get tinnitus. So, they'll have the same experience, and I'll talk about how horrible it is and how much they hate it so it's kind of doesn't bother[me] in that way". P^{UK9}

Future need for management and research: Given that tinnitus management for individuals who are deaf or severe-to-profoundly hearing-impaired is still being researched, the participants provided their thoughts on what they believed would be helpful for their condition. Regarding management, the participants' responses varied. Some believed that there would be no cure for tinnitus and that patients should learn to live with it. Others emphasised the importance of identifying the underlying cause of tinnitus. An instance of this was when a participant shared that the only perceived solution for their tinnitus was a

cochlear implant. However, they had not pursued this option because their audiologist advised against it, stating that a cochlear implant may exacerbate their tinnitus.

"They will never find a cure for tinnitus apart from a cochlear implant. [I] don't know what healthcare can do about it because it is just a chronic condition". P^{UK11}

Several participants expressed a strong desire for a solution for their tinnitus. If a cure was not possible, offering empathy and listening to those with tinnitus was considered to greatly alleviate some of the challenges it caused.

"[I] would like them to listen. And necessarily to sympathise. Oh, oh, there is an empathy you know. A support yes or no. How are you feeling? She says (refereeing to hearing therapist), you know, you will get used to it, though after a while. But [I] think every individual is different because some people have big spikes, you know, whereas mine generally, although [I] do get spied if I'm exposed to loud noises so it's a complicated thing, isn't it? Really?" P^{UK3}

One participant expressed his perspective on the management of tinnitus and emphasised the importance of personal training for CBT, as it has been shown to be effective in managing tinnitus.

"[I] want them to acknowledge that this is a serious problem as it can cause disability and force training which why I am always helping researchers for that…. Also, let everyone learn CBD because it is helpful". P^{UK4}

One participant expressed several views on addressing tinnitus in individuals who are deaf and suffer from tinnitus.

"We need a realistic goal which can work with us. Maybe concentrate on how to manage it or learn to live with it rather than expecting it will go away…also, we need more awareness among general population about the destructive effect tinnitus can have. We need to know the cause of tinnitus. Imaging studies can help in identifying part of the brain/ear/CNS. Then a physical intervention can take place one day". P[UK13]

Regarding research, participants expressed their perspective on what researchers should prioritise, with a focus on understanding the impact of tinnitus.

"*Definitely a lot more understanding of the condition and the impact it has on people's psychology and lives, definitely…..I guess it's the mental health issue for those people who are not quite as well and this is going to sound really cool. But there are people who, as with anything, such as, maybe there are people who use tinnitus as a and it's not that bad, but they're using it as a crutch because they want attention. You know, there are people I see. And I said, for example, I'm going to UK tinnitus support group on Facebook alone, but it's always the same people so not being productive but just actually wanting a moan mainly because that sounds awful. And not helping themselves".* P[UK12]

Several participants emphasised the importance of identifying the underlying causes of tinnitus, as this knowledge can lead to appropriate medical interventions.

"[I] suppose anybody could research what caused tinnitus in the first place? And secondly, what? Medical intervention you could get that might help"? P[UK10]

5.3.3 Mixed methods finding

Participants in this study had severe-to-profound hearing loss, with most having cochlear implants. All reported tinnitus and had experienced tinnitus for several years, many since

childhood or early adulthood. Tinnitus had a significant impact on the participants as evidenced by the questionnaire scores and then further illustrated by responses elicited in the semi-structured interviews. Tinnitus handicap varied from mild to catastrophic, and did not predict levels of anxiety, depression, or stress. Lower tinnitus handicap was generally associated with satisfaction with healthcare, support, and use of cochlear implants, whereas severe or catastrophic handicap was more likely associated with anxiety and dissatisfaction with healthcare providers. However, the relationship was not entirely predictable – participants with scores indicating mild or moderate tinnitus handicap gave accounts of real struggle with social interaction, often describing loneliness. One participant with mild tinnitus handicap scored as having the highest level of anxiety of all participants and had a moderate level of depression. Of the participants with catastrophic tinnitus handicap, one had mild depression and moderate anxiety, whereas the other two had no such symptoms. However, catastrophising was further evidenced in their interviews – what they described spoke of hopelessness; they reported isolation, a lack of help or benefit from support groups or their GP, and *"assume[d] nothing can be done"* and research will *"never find a cure"*.

5.4 Discussion

The current study investigated the lived experience of tinnitus in deaf and severe-profound hearing-impaired adults in a UK sample. Tinnitus had a great impact on the sample participants that was found in the questionnaires scores result and then further detailed in the semi-structured interviews.

5.4.1. Tinnitus severity and impact

In the current study, THI scores revealed varying levels of tinnitus impact, with three participants reporting a catastrophic effect on their daily lives. Tinnitus is highly prevalent among individuals with varying degrees of hearing loss, with the impact of tinnitus increasing

as hearing disability worsens (E. Beukes et al., 2021). The THI is distinct in its focus on the psychological/emotional aspects of tinnitus, followed by its effects on lifestyle, in comparison to other tinnitus questionnaires (Fackrell & Hoare, 2014). Additionally, it serves to assess the potential presence of psychiatric disorders, such as depression or anxiety, which may necessitate immediate intervention (Salviati et al., 2013).

5.4.2 Tinnitus-associated comorbidities

Participants in this study exhibited variable levels of depression, anxiety, and stress, a pattern commonly observed in tinnitus patients and documented in previous research (Beukes et al., 2021; Goderie et al., 2022; Teggi et al., 2025; Zhang et al., 2023). The mean score on the DASS-D (symptoms related to depression) was 9.6 (SD=11.6), indicating normal to mild depressive symptoms for most participants, with only three cases of severe or extremely severe depression. This variability aligns with broader findings in tinnitus research, emphasizing the heterogeneous nature of psychological comorbidities in tinnitus patients1.

Anxiety scores (DASS-A) averaged 7.8 (SD=10.9), showing more variability than depression scores. Nine participants had normal levels, while four reported moderate to extremely severe symptoms. This variability is consistent with previous findings, such as those reported by Goderie et al. (2022), which noted higher anxiety levels in individuals with new-onset or annoying tinnitus.

Interestingly, our study found a higher prevalence of anxiety than depression among participants, contrasting with some previous research. This discrepancy could be attributed to various factors, including the timing of our study, which coincided with the ongoing COVID-19 pandemic, a period marked by heightened health-related anxieties.

Stress levels, as measured by DASS-S, were predominantly normal (average 11.2, SD=8.6), with only three participants reporting mild to severe symptoms. These findings suggest that

stress levels were generally lower compared to depression and anxiety in this cohort, aligning with prior research indicating stress may be less pronounced than other psychological symptoms among tinnitus patients.

It's crucial to note that the DASS-21 measures symptom severity rather than providing clinical diagnoses. Caution is warranted when interpreting these scores, as tinnitus-related distress may confound self-reported items on depression or anxiety scales. Furthermore, our small sample size may not be fully representative of the broader tinnitus population, and factors such as specific demographics, tinnitus duration, and severity could influence the observed psychological symptom levels.

5.4.3 Interviews key findings

The onset of tinnitus was variable in the included sample and mostly associated with the onset of hearing loss at any age. Three participants who had been deaf since birth and early childhood stated that their tinnitus was always there, and one thought it was a normal sound to hear. This is exemplified by the case of a profoundly deaf individual with Waardenburg syndrome, who reported experiencing tinnitus all his life (Wheeler & Hopwood, 2015). For the remaining participants, tinnitus onset was associated with hearing loss that resulted from an incident. For example, head injury, noise exposure and receiving ototoxic medication are risk factors for tinnitus development (Langguth et al., 2013; Shore et al., 2016). Head injury in many cases affects the inner ear containing the cochlea where ototoxic medication and loud noises often affect hair cells and neuronal synapses.

The location of tinnitus varied between participants, but, surprisingly, those with a cochlear implant reported experiencing tinnitus in the same location as their implant. Therefore, when the cochlear implant was removed, tinnitus was still present. The presence of the cochlear

implant seemed to mask the tinnitus, and once it was removed, the tinnitus became noticeable.

Participants frequently mentioned the loudness of their tinnitus and how aware they were of the sound. Many of them said that the sound is always there and doesn't go away. However, they also noticed that if they pay too much attention to the sound, it becomes more distressing. This is supported by the findings of a cross-sectional study where individuals who complained about tinnitus were asked to answer questionnaires about how loud their tinnitus was, its onset, and how aware they were of it (Wallhäusser-Franke et al., 2012). The study included data from 4,705 people and found that higher subjective tinnitus loudness was associated with more severe distress Additionally, having hearing impairment in both ears was linked to perceiving tinnitus as louder.

The severity of tinnitus changed significantly for the majority of participants. The natural progression of tinnitus is frequently discussed in the literature (Dawes et al., 2020; Phillips et al., 2018), as its severity can either improve or worsen over time. Understanding this natural history can be valuable in counselling tinnitus patients, as it helps set realistic expectations about their condition. A cochlear implant played a key role in influencing the natural history of tinnitus, with some participants experiencing an increase in tinnitus intensity. As a result, the implant was often seen as either alleviating or exacerbating tinnitus symptoms.

Some of the participants also required validation for their tinnitus sound. For example, P^{UK2} believed that tinnitus was a normal sound that everyone heard. This finding helps explain why fewer individuals who are deaf since birth or early in life complain about tinnitus, even though they are likely experiencing it. Additionally, some participants only became aware of their tinnitus when they sought treatment for their hearing loss from an audiologist. This suggests that, in some cases, individuals may be more bothered by their hearing loss than their tinnitus, and it is important to screen for this distinction, as Henry (2015) stated. It also

emphasises the need for increased public awareness about tinnitus, especially among individuals who are Deaf or have severe-to-profound hearing loss.

The study highlighted several factors that can trigger or worsen tinnitus, with stress, sleep disturbances, and auditory strain being commonly reported by participants. One participant specifically mentioned that undergoing surgery requiring general anaesthesia could trigger their tinnitus, suggesting that medical procedures might play a role in its onset. While medications like acetaminophen are frequently linked to tinnitus, the relationship between specific drugs and tinnitus remains underexplored (Kim et al., 2021). Moreover, the stress involved in surgeries and other medical treatments could contribute significantly to the development or exacerbation of tinnitus. This points to the need for further research to understand how both medications and stressors, such as medical procedures, interact in triggering tinnitus, and underscores the importance of addressing these factors in managing the condition.

Several participants were severely affected emotionally. Tinnitus is known to affect people, but those who are severely impaired are affected the most (Colagrosso et al., 2019; Langguth et al., 2013, 2024; Pryce et al., 2023). One participant stated that she cannot handle tinnitus because coping strategies that she usually used at day would not work at night, which led to more stress and exhaustion. Part of the emotional impact is due to an inability to handle the tinnitus burden (Pryce et al., 2023). Pryce et al. (2023) found that individuals with tinnitus had to address their condition in two primary ways. Firstly, there was a sense of uncertainty that emerged from seeking assistance for tinnitus treatment. Secondly, managing tinnitus on their own led to feelings of abandonment among patients. Therefore, individuals with tinnitus had to manage their condition in their everyday lives, leading healthcare systems to hold patients responsible for their own treatment and wellbeing.

Tinnitus has a significant effect on the wellbeing of individuals who are severely affected by it. This includes difficulties with sleep, missing work, distancing themselves from family gatherings, and, ultimately, seeking isolation and avoidance. In the current study finding reported some participants experiencing various impacts, such as disrupted sleep or work-related issues, which ultimately led to early retirement and a cautious approach to social gatherings to avoid triggering their tinnitus. This finding aligns with a population-based hearing study conducted in Norway between 1996 and 1998, which included 21,754 adults (Jørgensen et al., 2022). The study found that individuals with both tinnitus and hearing loss were more likely to request sick leave compared to those with hearing loss alone. Furthermore, the presence of tinnitus and hearing impairment motivated individuals to seek disability benefits. Another study found that the need for recovery, which includes feelings of overload, irritability, social withdrawal, work overload and reduced performance, was not directly linked to tinnitus (Simons et al., 2023). However, the study did find a strong association between the presence of psychological distress, such as depression and somatisation, and the need for recovery. These psychological distress factors are often closely connected to tinnitus.

The presence of tinnitus can lead to difficulties in falling asleep or staying asleep, which aligns with previous research indicating a positive association between tinnitus, fewer hours of sleep, and existence of stress (Kim et al., 2015). In respect to coping strategies, participants in the current study sample reported similar coping strategies to manage their tinnitus, which they had developed over time, with habituation being the most prominent. They often expressed their habituation mechanism by using phrases like "I adapt to the sound" or "I am used to it". Participants sought advice despite believing it would not be effective for their condition. Pryce et al. (2023) supported this finding, indicating that some participants would

engage in a cycle of seeking multiple opinions and visiting various clinics for further investigation. Many individuals in that study with tinnitus did not seek treatment because they did not view it as a significant issue, prioritising their main concern of deafness instead. This was observed among most of the included participants in the current study. This finding aligns with the perspective shared by Henry et al. (2015), who noted that for many patients, deafness is a more pressing problem than tinnitus. In the study, many individuals with tinnitus did not seek treatment, as they did not perceive it as a significant issue, often prioritizing their primary concern of hearing loss. This pattern was consistent across most participants in the current study. Henry et al. (2015) also, who observed that for many patients, hearing loss is a more urgent concern than tinnitus (Henry et al., 2015). However, a few participants who did seek treatment for their tinnitus reported negative experiences with healthcare providers. These encounters were often marked by a lack of understanding of their condition, unrealistic advice, and other issues, which resulted in increased emotional distress, heightened depression, and a loss of trust in the healthcare system.

Support was clearly evident among the participants in the study, with many receiving encouragements from family members who expressed sympathy for their condition, as well as from friends who understood the challenges they were facing. This emotional support played a significant role in helping participants cope with the difficulties of living with tinnitus, providing them with a sense of understanding and solidarity during their experiences.

Several participants in the study were actively advocating for solutions to their tinnitus and expressed strong enthusiasm for potential treatments. One participant specifically suggested encouraging the use of CBT as a treatment option for tinnitus. CBT has been widely recognised as an effective approach for managing tinnitus, with numerous studies documenting its benefits in helping individuals cope with the emotional and psychological

aspects of the condition (Cima et al., 2018, 2019; Fuller et al., 2020). This therapy focuses on changing negative thought patterns and behaviours, which can help reduce the distress caused by tinnitus. However, while CBT is strongly recommended for tinnitus management, it is important to note that its effectiveness can vary among individuals, and more research is needed to explore its full potential and the best ways to integrate it into broader treatment plans for tinnitus.

In terms of research, participants call for a deeper understanding of tinnitus's psychological and life impacts, as well as studies to identify its underlying causes, potentially through imaging studies. Setting realistic goals, such as focusing on management rather than a cure, and increasing public awareness about tinnitus's destructive effects are also emphasized. Overall, a holistic approach combining interdisciplinary research, personalized treatments, and comprehensive support is crucial for improving the quality of life for those affected by tinnitus.

5.5 Conclusion

The current study highlighted the profound impact of tinnitus on deaf and severe-profound hearing-impaired adults in the UK, revealing considerable variation in both the severity of tinnitus and its associated psychological comorbidities, such as depression, anxiety, and stress. Quantitative assessments using validated tools underscored how tinnitus can catastrophically disrupt daily living for some, while semi-structured interviews detailed individual coping mechanisms, emotional responses, and the heterogeneous nature of the condition.

The onset and perception of tinnitus varied widely among participants, particularly influenced by hearing loss events, cochlear implant usage, and personal interpretation of their symptoms. Notably, the emotional and psychological toll was most pronounced in those with severe

impairment, manifesting as sleep disturbances, social withdrawal, and greater vulnerability to stressors, including medical interventions. Support from family and peers played a crucial role in mitigating the effects and fostering resilience.

A recurring theme was the importance of individualized coping strategies, with habituation and cognitive behavioural approaches recognized as promising but imperfect solutions. Participants also expressed frustration with healthcare responses, emphasizing the need for greater provider awareness and holistic care—an aspect strongly supported by current tinnitus guidelines which advocate evidence-based, person-centred management.

Given the complexity and unpredictability of tinnitus future research should prioritize multidisciplinary perspectives, real-world treatment efficacy, and imaging-based studies to uncover underlying mechanisms. Enhancing public and provider awareness, tailoring support services, and advancing holistic therapy options remain key to improving quality of life for those affected.

Chapter 6: Mapping the tinnitus-related problems of deaf adults to tinnitus questionnaires

6.1 Introduction

The utilization of both quantitative and qualitative methods was employed to assess the impact of tinnitus in two distinct populations: a Saudi sample (Chapter 4) and a UK sample (Chapter 5).Methods included the THI and DASS alongside semi-structured interviews that allowed participants to articulate their lived experiences.

In the Saudi sample, participants struggled with the Arabic version of the THI, citing issues such as the irrelevance of some questions to their specific condition. Despite or because of this, their THI scores indicated a mild tinnitus impact on average. However, when participants were interviewed, they revealed significant disruptions in personal, family, and work-related aspects of their lives. This discrepancy suggests that the THI, in its current form, may not accurately capture the complexity of tinnitus impact in this population.

In contrast, the UK sample reported no difficulties completing the THI, and their scores indicated a moderate tinnitus impact on average. Given the widespread use of the THI in the UK, it is likely that participants were more familiar with the instrument, which could have influenced their ability to complete it with relative ease. However, the qualitative interviews revealed that tinnitus had a profound impact on the participants' lives, indicating that the THI, while useful, does not fully reflect the broader, nuanced experiences of individuals living with tinnitus.

The findings raise important questions regarding the suitability of the THI for assessing tinnitus severity, particularly for individuals who are D/deaf or have severe-to-profound hearing impairments. Given that the THI is the most frequently used instrument in tinnitus assessment, as noted in the systematic review by Hall et al. (2016), these concerns highlight

the need for a more tailored assessment tool. Hall et al. (2016) aimed to identify the frequently reported outcome domains and instruments in tinnitus research, with the THI emerging as the most widely used tool (n=24) across 288 studies. Their review, which examined both primary and secondary outcomes in clinical trials, acknowledges hearing impairment as a common co-occurring issue among tinnitus patients (Hall et al., 2016). Moreover, the review underscored the need for standardisation in tinnitus research, stressing the importance of consistent outcome measures to improve the quality and comparability of studies. This reinforces the necessity of developing more inclusive and accurate assessment tools to better address the diverse needs of tinnitus patients (Hall et al., 2016). So, the question that arises here is whether the THI accurately captures the tinnitus impact experienced by individuals who are deaf or have severe-to-profound hearing impairments, given that it does not assess any aspects of hearing.

Questionnaires in general are essential patient-reported outcome (PRO) tools that gather data directly from patients to help healthcare providers determine treatment strategies (Lasch et al., 2010; Patrick et al., 2011). The development of these tools involves several steps: defining study objectives, designing clear and unbiased questions, ensuring a logical flow, and maintaining engagement through appropriate length and format (Rameshbhai Patel & Joseph, 2016; Rattray & Jones, 2007; Song et al., 2015). In the case of pre-existing questionnaires, it is essential to confirm that these tools are appropriately designed for their intended purpose through validation, as outlined by Song et al. (2015). Validation of a questionnaire can be assessed through one of three main types of validity, often referred to as the “Three Cs”: Content validity, Construct validity, and Criterion-related validity. Content validity ensures that the questionnaire comprehensively covers all relevant aspects of the topic it is intended to measure. Construct validity confirms that the questionnaire accurately measures the intended concept or construct without including irrelevant or extraneous factors.

Criterion-related validity assesses the correlation between the questionnaire and other established, reliable measures of the same construct, ensuring its predictive or concurrent relevance. Finally, face validity involves expert judgment on whether the questionnaire appears to be appropriate and relevant for measuring the intended concept, based on a surface-level inspection. By confirming these types of validity, one can ensure that the questionnaire is both accurate and reliable for its intended use.

Despite the availability of numerous validated tinnitus questionnaires, there remains a gap in the market for tools tailored to individuals who are D/deaf and or have severe-to-profound hearing impairments. Currently, no tinnitus questionnaire has been developed to specifically addresses the needs of this population, underscoring the need for further research to determine whether any existing questionnaires are fit for purpose, or whether appropriate instruments need to be developed (NICE, 2020). To address this with respect to deaf adults with tinnitus, this chapter will use a content analysis approach to map patient-reported complaints against existing frameworks to the items in existing tinnitus questionnaires, with the goal of identifying the most suitable instruments for the individuals included in this PhD. This will lay the groundwork for selecting or creating more reliable and inclusive assessment tools for future clinical trials and treatment interventions for tinnitus in deaf adults.

The Core Outcome Measures in Tinnitus (COMiT'ID) initiative has been pivotal in standardising the tools used to assess tinnitus by identifying a minimum set of outcomes that should be measured in tinnitus studies (Hall, Smith, et al., 2018). This is crucial for ensuring that these outcomes are meaningful and relevant to patients. The COMiT'ID project was specifically designed to develop a Core Outcome Set (COS) for tinnitus, a condition that often manifests uniquely for each patient and has wide-ranging impacts on quality of life. The initiative, which involves collaboration between researchers, clinicians, and patients, aims to ensure that these key outcomes reflect the experiences of those affected by tinnitus, providing

a more comprehensive and patient-centred approach to treatment and research (Hall, Smith, et al., 2018)

A Core Outcome Set (COS) refers to the essential set of outcomes that should be consistently measured and reported in studies of a particular health condition. This set is typically determined through a consensus process involving key stakeholders, including clinicians, patients, and researchers (Williamson et al., 2012). The inclusion of patients as central stakeholders in this process is particularly important, as it ensures that the outcomes chosen are not only clinically relevant but also aligned with the aspects of the condition that matter most to those living with it.

In the case of tinnitus, the COMiT'ID initiative is an example of a collaborative effort that has worked towards ensuring that both clinical and patient perspectives are taken into account. While clinicians often focus on detailed, measurable symptoms, patients' concerns are typically more holistic, involving the overall impact of the condition on their lives. This divergence in focus means that involving patients alongside clinicians in defining outcome measures is vital to ensuring that the outcomes assessed reflect the full scope of tinnitus's effects. Dodd et al. (2023) argue that patient involvement offers a unique perspective, one that can help highlight the broader, lived experience of the condition—perspectives that might otherwise be overlooked in a purely clinical context (Dodd et al., 2023).

The importance of patient involvement in the development and validation of assessment tools is underscored by Smith et al. (2018), who emphasise that patient input ensures that instruments are more reflective of the real-world experiences of individuals with tinnitus. This approach leads to more relevant and effective clinical evaluations, as the questionnaires and tools created are tailored to capture the nuanced, subjective nature of tinnitus (Smith et al., 2018). In conditions like tinnitus, where the impact is profoundly individual, this patient-

centerer approach is particularly essential. It allows for a deeper understanding of the condition and ensures that treatments and assessments are better aligned with what truly matters to patients.

In evaluating available questionnaires, frameworks like the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) are crucial for ensuring high-quality, reliable, and valid instruments (Mokkink et al., 2024; Terwee et al., 2018). COSMIN provides a framework for improving the selection of health measurement instruments, ensuring that the tools used in clinical and research settings are of high quality and appropriate for the target population. This initiative emphasises the importance of rigorously assessing measurement properties, such as reliability, validity, and responsiveness, to ensure that the instruments used in research and clinical practice provide accurate, meaningful data.

6.1.1 Aim

The purpose of this study was to determine whether any of the many available tinnitus questionnaires are suitable for measuring the most common tinnitus related problems reported by adults who are Deaf or have severe-to-profound hearing-impairment

6.1.2 Objectives

There are no available tinnitus questionnaires known to address the need for deaf and severe-profound hearing-impaired adults, hence, the objectives of this study were:

1. To quantify problems among the study samples in Chapters 4 and 5 through content analysis against an established tinnitus problem domain framework, and
2. To map the most frequently reported problems to available tinnitus questionnaires through examining its content validity.

6.2 Method

6.2.1 Stage 1: Identification of Commonly Reported Problems Across Study Samples Using Qualitative Content Analysis

A deductive content analysis was employed. Content analysis is a systematic approach that enables valid inferences to be drawn from verbal, visual, or written data, describing and quantifying specific phenomena (Bengtsson, 2016; Elo & Kyngäs, 2008). This method involves breaking data into smaller units—such as codes or keywords—and quantifying the frequency of these keywords within the dataset. Two key approaches within content analysis are manifest and latent analysis. Manifest analysis focuses on the surface-level, literal meaning of the data, while latent analysis seeks to uncover deeper, hidden meanings (Bengtsson, 2016). The processes of content analysis can vary among researchers, but typically include preparation, data collection and organisation, followed by interpretation and reporting of findings (Bengtsson, 2016; Elo & Kyngäs, 2008).

During the preparation and planning phase, two researchers (LA and MS) independently reviewed the data to identify keywords indicating tinnitus-related issues across the scoping review (Chapter 3), and SA (Chapter 4) and UK (Chapter 5) samples. The extracted keywords were then compiled into an Excel spreadsheet (Appendix 10). For this study, keywords were defined as the specific problems reported by participants during interviews concerning the impact of their tinnitus. Manifest analysis was employed in this stage, as the objective was to identify visible aspects of the data that could be categorised, counted, and analysed objectively. The focus was on identifying explicit content patterns, without delving into subjective interpretations. To ensure accuracy, the extracted problems reported by samples, were compared and discussed among stakeholders, and final group discussions involving a third researcher (DH) finalised the keyword list.

The extracted problems were organised into categories based on tinnitus-related complaints as outlined by Hall et al. (2018a) whose study analysed data from 84 studies and classified tinnitus-related complaints reported by patients and their significant others. These complaints were derived from both closed-ended questions (e.g., questionnaires or numerical rating scales) and open-ended questions (e.g., structured interviews) (Hall et al., 2018a). Subsequently, these complaints were classified according to the World Health Organization's (WHO) framework into five main domains (Table 6.1).

Table 6.1 Tinnitus-related problems based on WHO classification (adapted from Hall et al. 2018a)

Domains (WHO)	Group domains	Problems
Physical health	Physical health problems	▪ Sleep difficulties ▪ Bodily concern ▪ Difficulties relaxing ▪ Feeling tired ▪ Pain ▪ Loss of appetite
Psychological	Functional difficulties due to tinnitus	▪ Negative effects on hearing ▪ Concentration difficulties ▪ Cognitive difficulties ▪ Ability to ignore
	Negative thoughts about tinnitus	▪ Loss of control ▪ Change in sense of self ▪ Suicidal thoughts ▪ Loss of peace ▪ Irrational beliefs
	Tinnitus-related distress	▪ Annoyance ▪ Worries/concerns ▪ Irritable ▪ Distress form bodily sensations ▪ Fear ▪ Frustration
	Mood states	▪ Anxiety

	General distress	▪ Depressive symptoms ▪ Lack of joy ▪ Anger
Level of independence/ mobility social relationships environment	Health related quality of life Quality of life associated tinnitus	▪ Negative impact on activities • Negative impact on social life • Negative impact on work activities • Negative impact on individual activities ▪ Difficulties coping ▪ Negative impact on relationships ▪ Lack of support from family and friends ▪ Sexual difficulties
Negative attributes of tinnitus sound	Tinnitus loudness Tinnitus awareness Tinnitus intrusiveness Tinnitus pitch Tinnitus location Tinnitus unpleasantness	
Miscellaneous	Depression Need for knowledge Acceptance of tinnitus Reduced sound tolerance	

The five main domains discussed included physical health, psychological well-being, level of independence and mobility, the negative contributions of tinnitus, and miscellaneous factors. The physical health domain addresses issues such as sleep difficulties and bodily concerns. The psychological domain covers various impacts of tinnitus, including functional difficulties (e.g., hearing, concentration, cognitive challenges), negative thoughts about tinnitus (e.g., loss of control, self-identity changes, suicidal thoughts), and tinnitus-related distress (e.g., worry, fear, annoyance). The independence and mobility domain examines the effects of tinnitus on social life, work, and personal activities, along with difficulties in coping and relationship strain. The fourth domain focuses on the negative qualities of the tinnitus sound itself, including its loudness, intrusiveness, pitch, and the individual's awareness of it. The miscellaneous domain includes factors such as depression, acceptance of tinnitus, and the need for further information or support.

To identify the most reported complaints across the study samples, two researchers (LA and DH) quantified the frequency of reported problems across the UK and SA samples. This quantification step provided a numerical basis for comparison and allowed for the identification of the most frequently reported problems. Each problem was counted once per participant, and the overall frequency of mentions across each sample was tallied. Four mentions were established as the threshold for identifying the most frequently reported problems, in consideration of the relatively small sample size and to ensure that the analysis remained manageable and meaningful.

6.2.2 Stage 2: Content Validity of the Available Tinnitus Questionnaires to the Reported Problems Extracted from the Interviews

The aim of this stage was to assess the content validity of existing tinnitus questionnaires to determine their suitability for measuring the specific problems identified. Specifically, this stage evaluated how well current tinnitus questionnaires map to frequently reported problems of adults with severe-to-profound hearing loss or those who are D/deaf. Content validity refers to the extent to which an instrument accurately measures what it intends to measure (Zamanzadeh et al., 2014). It is an essential measurement property of a Patient-Reported Outcome Measure (PROM) and is typically assessed using three parameters: relevance, comprehensiveness, and comprehensibility (L. Mokkink et al., 2024; Terwee et al., 2018). Relevance concerns whether the items included in a questionnaire are appropriate for the construct being measured, the target population, and the context of use. Comprehensiveness involves assessing whether a questionnaire's items are sufficiently broad and thorough to cover the key concepts. Comprehensibility is the ability of the target sample to understand the questionnaire, e.g., the clinician, researcher, or patient. Due to the retrospective nature of the analysis in this chapter, assessment of comprehensibility was not formally assessed although it was clear that for many Saudi Arabian participants the THI was not entirely comprehensible (Chapter 4).

A systematic approach was employed to identify relevant tinnitus questionnaires, including reviewing published literature (Haider et al., 2016; Hall et al., 2016) and conducting manual searches using Google Scholar and PubMed to ensure a comprehensive inclusion of both established and more recently developed instruments. Figure 6.1 illustrates the process of identifying tinnitus questionnaires.

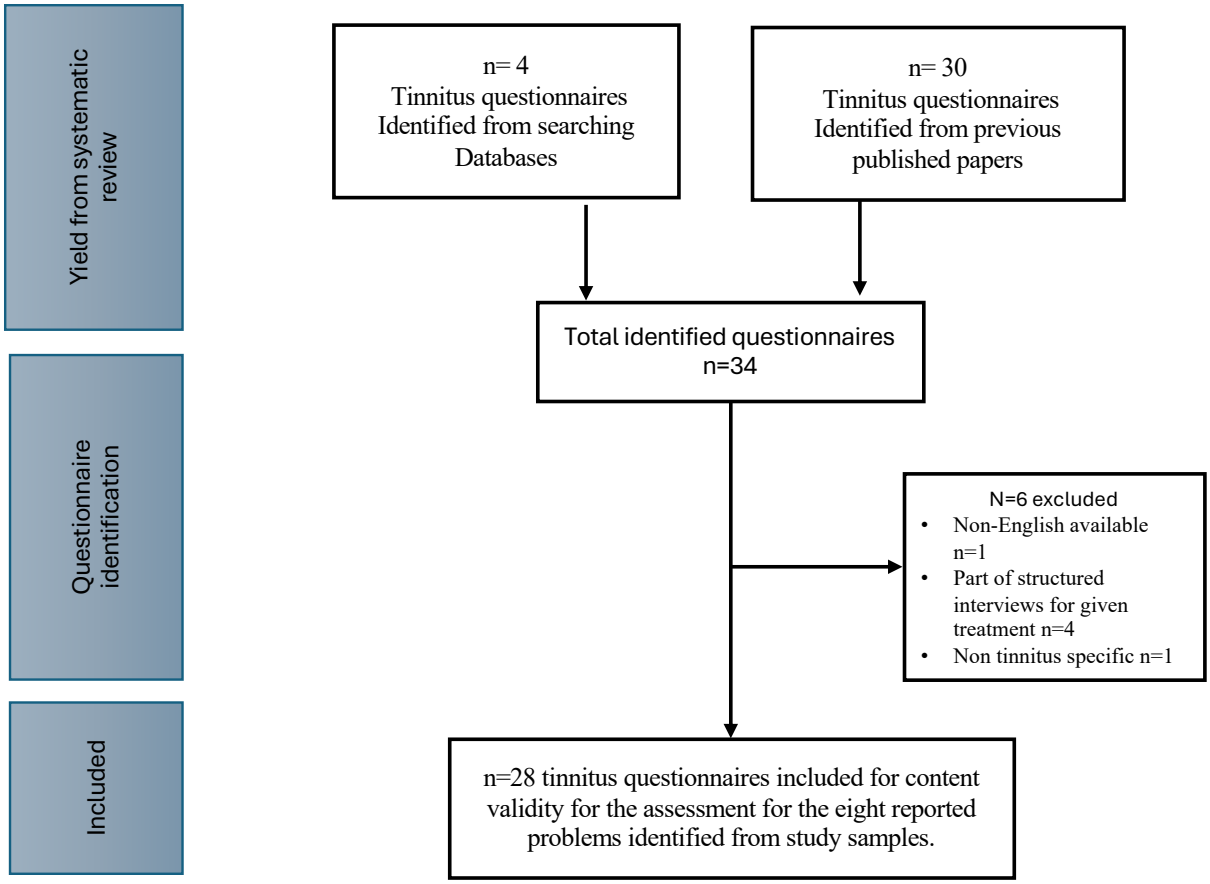


Figure 6.1 The process of identifying and including tinnitus questionnaires to be assessed for content validity of the identified reported problems.

Twenty-eight tinnitus questionnaires were included for content validity assessment (Table 6.2)

Table 6.2 Characteristic of the included tinnitus questionnaires.

No	Questionnaire	Authors/ year (Country)	Aim	Subscales (no. items)
Q1	Tinnitus Questionnaire	Hallam et al/ 1988 (United Kingdom)	To assess psychological aspects of tinnitus	5 subscales (52) 1. Emotional and cognitive distress 2. Intrusiveness 3. Auditory perceptual difficulties 4. Sleep disturbances 5. Somatic complaints
Q2	Mini TQ12	Gobel and Hiller/ 2004 (Germany)	To assess the psychological aspects of tinnitus and treatment responsive.	3 subscales (12) 1. Emotional and cognitive distress 2. Intrusiveness 3. Sleep disturbances
Q3	Tinnitus Handicap Questionnaire	Kuk et al /1990 (USA)	To measure patients' perceived degree of handicap due to tinnitus	3 factors (27) 1. Physical, emotional and social effects of tinnitus 2. Hearing and communication ability 3. Individual's perception of tinnitus
Q4	Tinnitus Severity Scale	Sweetwo & Levi /1990 (USA)	To assess tinnitus severity	No subscales (27)
Q5	Subjective Tinnitus Severity Scale	Halford & Anderson/ 1991 (United Kingdom)	To develop a straightforward scale, which yielded a single severity score (severity of tinnitus)	Intrusiveness (16) Prominence of tinnitus Distress

Q6	Tinnitus Reaction Questionnaire	Wilson et al. /1990 (Australia)	To assess the psychological distress associated with tinnitus. To distinguish tinnitus sufferers who cope with tinnitus from those who do not cope well	4 factors (26) 1. General distress 2. Interference 3. Severity & 4. Avoidance
Q7	Tinnitus Severity Index	Meikle et al. /1995 (USA)	Measures the negative effects of tinnitus on patients' life	No subscale (12)
Q8	Tinnitus Coping Style Questionnaire	Budd & Pugh/ 1996 (United Kingdom)	Assess on the coping style developed by tinnitus suffers	3 domains (40) Maladaptive, effective and passive coping)
Q9	Tinnitus Handicap Inventory	Newman et al. /1996 (USA)	Measure impact of tinnitus on everyday function	3 subscales (25) 1. Functional effect of tinnitus 2. Emotional response to tinnitus 3. Catastrophic response to tinnitus
Q10	Tinnitus Cognitions Questionnaire	Wilson & Henry/ 1998 (Australia)	To assess the content of a person's cognitions in relation to tinnitus.	2 factors (26) Negative and positive cognition
Q11	International Tinnitus Inventory	kennedy et al./ 2005 (Netherlands)	To assess tinnitus main complaints in fast and roboust measure.	Eight problems (8) The perceived effect of tinnitus on hearing, health, sleep, peace of mind, other people, activities, enjoyment of life as well as the sense of annoyance generated by the tinnitus.
Q12	Chronic Tinnitus Acceptance Questionnaire	Moreland/ 2007 (United Kingdom)	To evaluate the efficacy of acceptance-orientated treatment	No subscales (20)

Q13	Tinnitus Acceptance Questionnaire	Westin et al. /2008 (Sweden)	To investigate the role of psychological acceptance in tinnitus sufferers	2 subscales (12) 1. activity engagement 2.tinnitus suppression
Q14	Fear of Tinnitus Questionnaire	Cima et al. 2011/ (Netherlands)	To assess tinnitus associated fear	No subscales (17)
Q15	Tinnitus Catastrophizing Scale	Cima et al. 2011/ (Netherlands)	To assess tinnitus associated catastrophizing	No subscales (13)
Q16	Tinnitus Vigilance and Awareness Questionnaire	Cima et al. 2011/ (Netherlands)	To assess tinnitus awareness toward tinnitus	No subscales (18)
Q17	Tinnitus disability Index	Cima et al. 2011/ (Netherlands)	To assess of the interference of tinnitus with performance in specific daily life activities.	Two subscales (7) Voluntary activities obligatory activities

Q18	Self-Efficacy for Tinnitus Management Questionnaire	Smith & Fagelson/ 2011 (USA)	To assess the level of tinnitus self-efficacy. The results of the tinnitus questionnaire could then be used clinically to identify areas that need to be targeted in tinnitus treatment approaches, especially those incorporating self-efficacy principles, and to monitor tinnitus self-efficacy before, during, and after the course of treatment as an outcome measure.	5 subscales (40) (1) routine tinnitus management, (2) emotional response to tinnitus, (3) internal thoughts and interaction with others, (4) tinnitus concepts, and (5) use of assistive devices
Q19	Tinnitus Fear Avoidance Scale	Kleinstauber et al. /2013 (Germany)	To assess the role of fear-avoidance behaviour in tinnitus handicap which could help in psychotherapy	3 factors (14) Cognitions, Ear related and tinnitus related fear-avoidance behaviour

Q20	Tinnitus Functional Index	Meikle et al. / 2011 (USA)	To Provide the broadest assessment of tinnitus impact	Eight domains (25) 1.intrusiveness 2.sense of control 3. cognition 4.sleep 5. auditory, 6. relaxation, 7. quality of life 8. emotional distress
Q21	Tinnitus Magnitude Index	Schmidt et al. /2014 (USA)	To provide a unique domain describe the intensity of tinnitus (loudness)	No subscales (3)
Q22	Tinnitus Primary Function Questionnaire	Tylor et al. / 2014 (USA)	To assess tinnitus primary handicap	4 domains (20) 1. Hearing 2. Emotion 3. Sleep 4. Concentration
Q23	Tinnitus Primary Function Questionnaire	Tylor et al. / 2015 (USA)	To assess tinnitus primary handicap which is brief	4 domains (12) 1. Hearing 2. Emotion 3. Sleep 4. Concentration
Q24	Tinnitus and Hearing Survey	Henry et al. /2015 (USA)	To provide assessment tool to differenate hearing problems from tinnitus complaints	3 subscales (10) Hearing, tinnitus & sound intolerance)

Q25	Skarzynski Tinnitus Scale	Skarzynski et al. /2018 (Poland)	To evaluate tinnitus compliant in adult with normal or impaired hearing	3 subscales (18) 1. Psychological 2. Functional 3. coping
Q26	FiveQ	Connell et al. /2022 (Australia)	To provide a targeted tinnitus questionnaire that can assess tinnitus severity efficiently and fast	Five domains (26) 1. Sleep 2. Concentration 3. relaxation 4. Daily activity 5. Hearing
Q27	TIQ	Aazh et al. /2024 (United Kingdom)	To assess tinnitus impact on everyday life activities, mood and sleep and not hearing difficulties	No subscales (7)
Q28	4C	Aazh et al. /2024 (United Kingdom)	To evaluate patient confidence in the management of tinnitus following CBT	No subscales (4)

Three researchers (LA, MS, and RSD) independently rated each item for relevance by mapping them onto an Excel spreadsheet. Items were scored on a scale from 1 to 3, where 3 indicated high relevance, 2 indicated low relevance, and 1 indicated no relevance. If two or more researchers scored an item as 3, it was considered relevant. If only one researcher scored it as 3, the item was subject to further discussion and judgement by fourth researcher (DH), and if no researchers scored it 3, the item was excluded as not highly relevant. Next the agreed results were scored as True or False on the final relevance decision. An example of one questionnaire items coding and its final decision are shown in appendix 11

Relevance was quantified as the percentage of relevant items over the total number of items in the questionnaire. For example, if a questionnaire contained 27 items, with three items relevant to sleeping difficulties and one item relevant to tinnitus awareness, the relevance for sleeping difficulties would be calculated as 11% (3/27) and for tinnitus awareness as 3.7% (1/27). Comprehensiveness was assessed based on whether items addressing all key domains for the given sample were included. A questionnaire was deemed comprehensive if all domains relevant to the target population were covered regardless of the number of items relevant for different domains.

6.3 Results

6.3.1 Stage 1. Frequently reported problems

A total of 26 problems were identified across the three study samples—the scoping review and lived experience samples from SA and UK participants. These problems were mapped to the WHO domains as outlined by Hall et al. (2018a), and the results are presented in Table 6.3

Table 6.3 Reported problems among study samples.

Domain		Scoping review	UK sample	SA sample
PHYSICAL HEALTH	*Physical health problems*	Sleep difficulties, bodily complaint, pain	Sleep difficulties, bodily complaint, feeling tired and pain	Sleep difficulties, bodily complaint, Difficulties relaxing and pain
PSYCHOLOGICAL	*Functional difficulties due to tinnitus*		Concentration difficulties	Concentration difficulties
	Tinnitus related distress		Annoyance, irritable, fear and frustration	Annoyance and fear
	Negative thoughts about tinnitus	Lack of control		
	Mood states	Anxiety, depression		
LEVEL OF INDEPENDENCE/MOBILITY SOCIAL RELATIONSHIPS ENVIRONMENT	*Negative impact on activities*		Negative impact on social life Negative impact on work	Negative impact on social life Negative impact on work Lack of support from family and friends

NEGATIVE ATTRIBUTES OF TINNITUS SOUND	Tinnitus loudness	Tinnitus loudness Tinnitus awareness Tinnitus intrusiveness	Tinnitus loudness

For example, from the UK sample, keywords such as “wake up” and “trouble falling asleep” were categorised under “sleep difficulties” and associated with the Physical Health domain, while “concentration difficulties” were categorised under the psychological domain (Table 6.2). The frequency with which participants mentioned each of the problems in each domain is presented in the Figures 6.2 to 6.6.

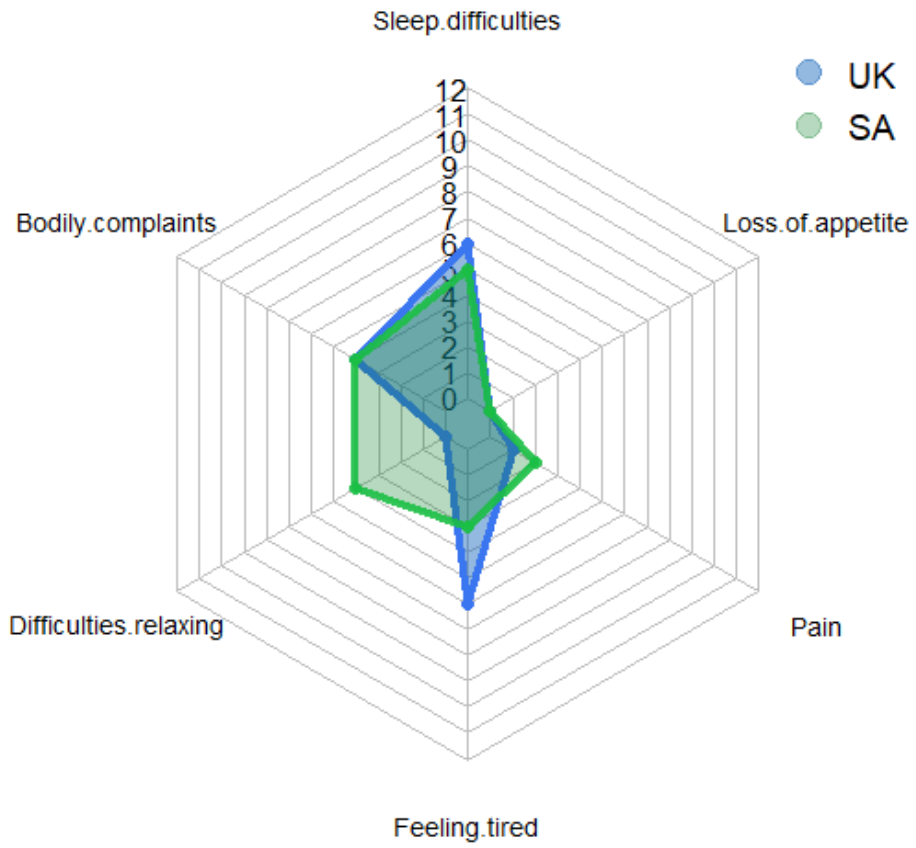


Figure 6.2 Reported problems in physical domains in the United Kingdom (UK, in blue) and Saudi Arabia (SA, in green) samples. Spider diagram shows the frequency of individual reporting problems in each sample (n=13).

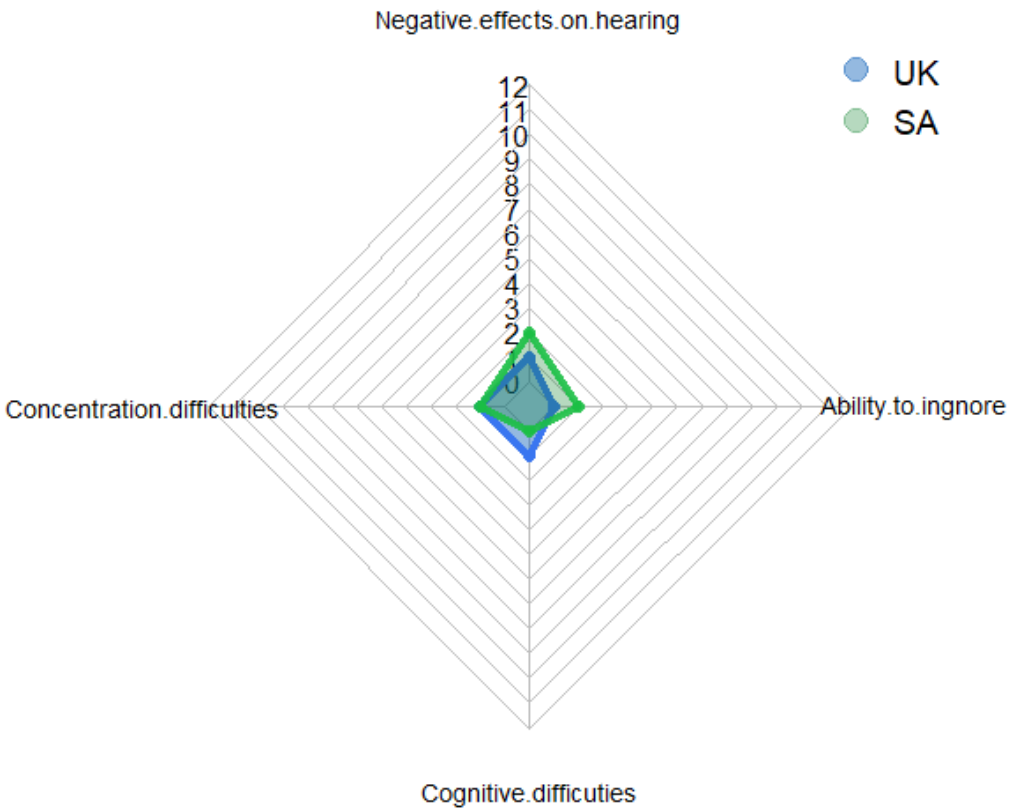


Figure 6.3 Reported problems in psychological domains-functional difficulties due to tinnitus in the United Kingdom (UK, in blue) and Saudi Arabia (SA, in green) samples. Spider diagram shows the frequency of individual reporting problems in each sample (n=13)

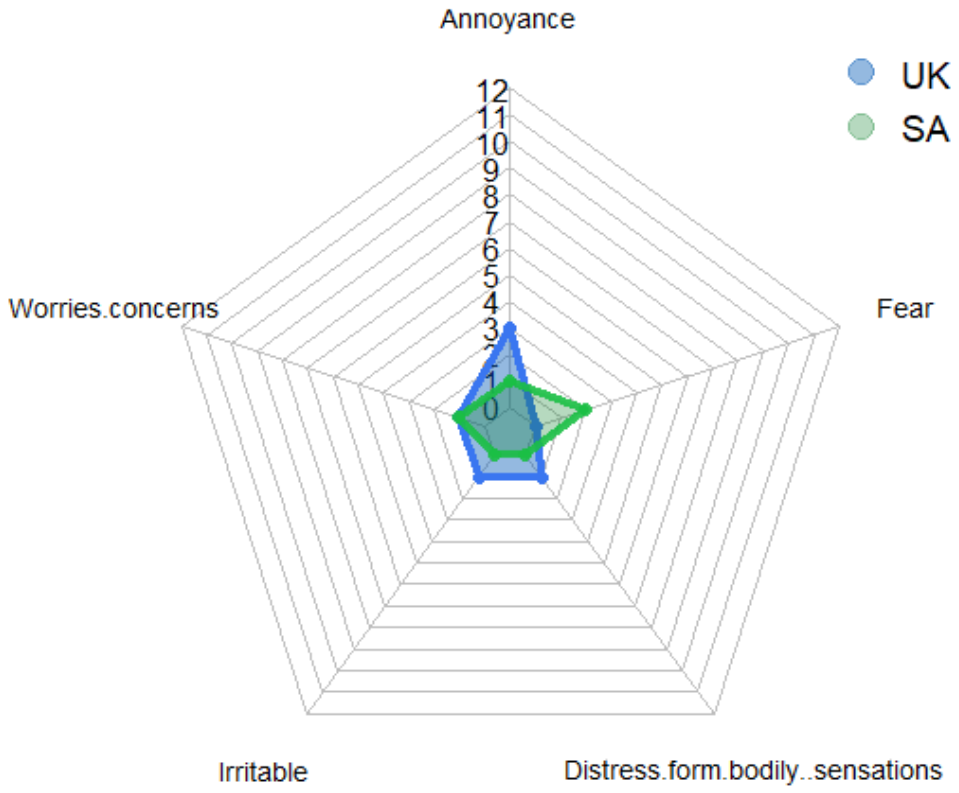


Figure 6.4 Reported problems in psychological domains- tinnitus related distress in the United Kingdom (UK, in blue) and Saudi Arabia (SA, in green) samples. Spider diagram shows the frequency of individual reporting problems in each sample (n=13)

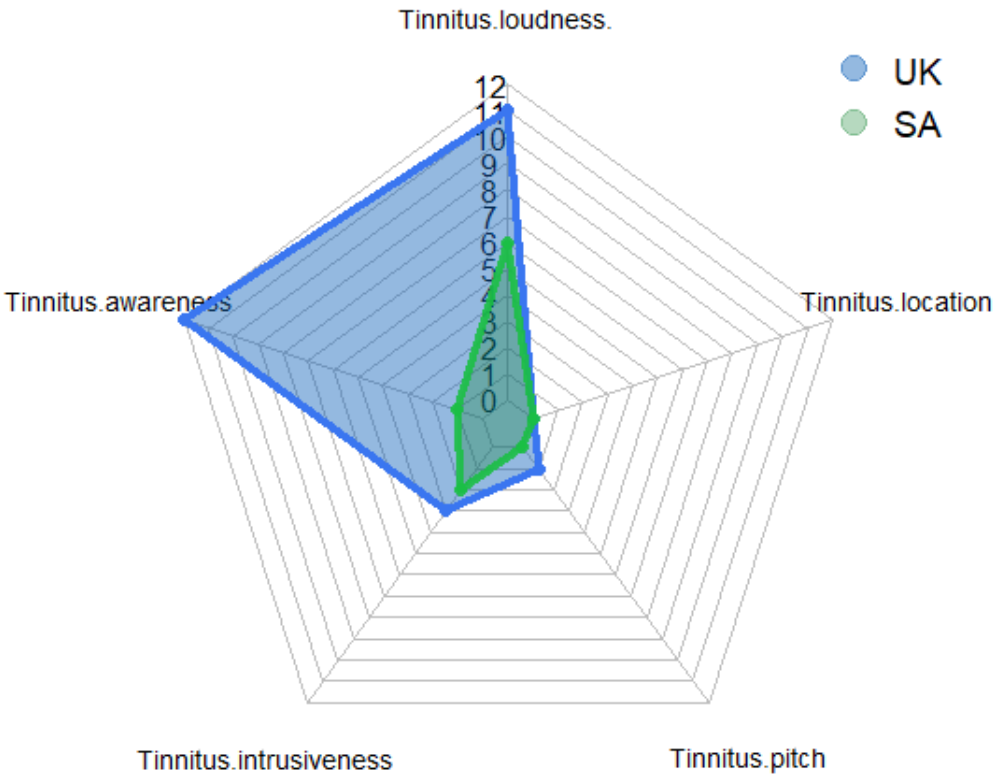


Figure 6.5 Reported problems in the negative attributes of tinnitus sound in the United Kingdom (UK, in blue) and Saudi Arabia (SA, in green) samples. Spider diagram shows the frequency of individual reporting problems in each sample (n=13)

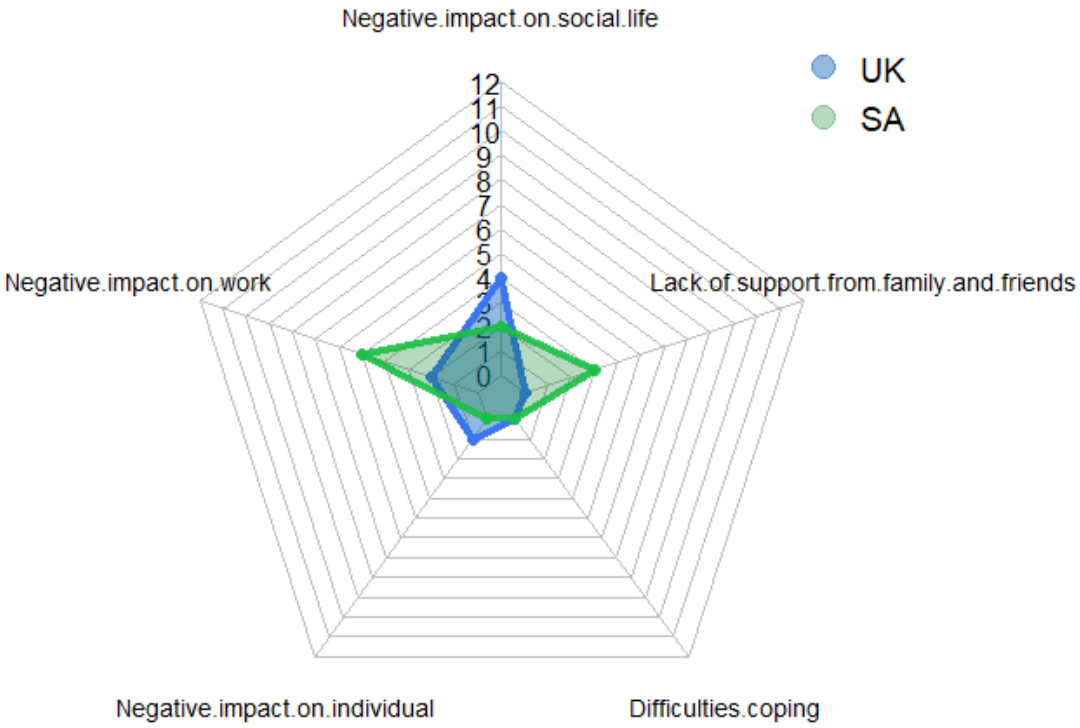


Figure 6.6 Reported problems in the independence domain in the United Kingdom (UK, in blue) and Saudi Arabia (SA, in green) samples. Spider diagram shows the frequency of individual reporting problems in each sample (n=13)

Eight problems across three main domains were identified and mapped for the next stage of analysis (Figure 6.7).

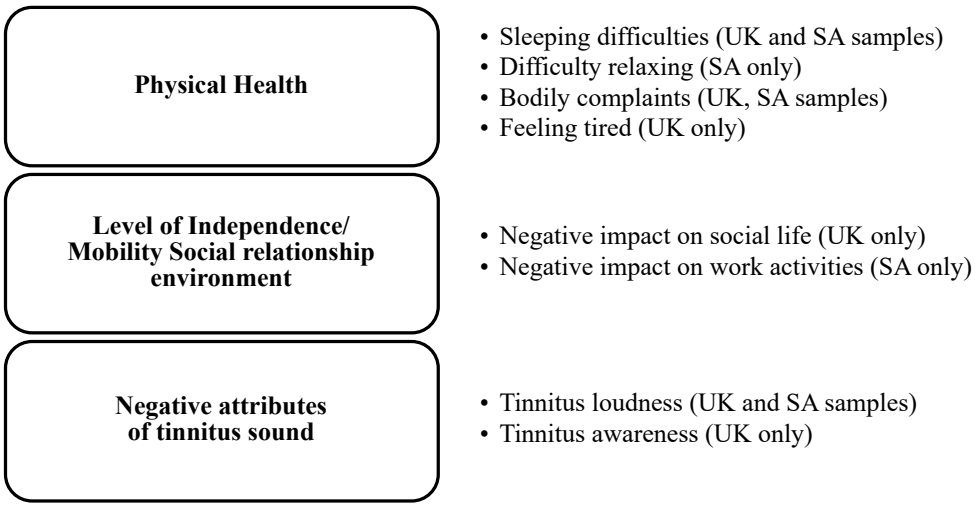


Figure 6.7 The most reported problems in the UK and SA study samples under the three main domains: Physical, Level of Independence, and Negative Attributes of Tinnitus Sound.

The eight problems among the study samples were mapped across the included questionnaires in the next step.

6.3.2 Stage 2: Content Validity

Searches yielded 28 questionnaires with a total of 512 items. The highest numbers of items in a questionnaire were in the Tinnitus Questionnaire (52 items) and Tinnitus Self-Efficacy Questionnaire (40 items) whereas the lowest were in the 4C Tinnitus Management Questionnaire (4 items) and Tinnitus Magnitude Index (3 items). In terms of country of origin, 10 questionnaires were from the United States of America, six from the UK, five from Netherlands, three from Australia, two from Germany, and one each from Poland and Sweden.

Content validity assessment revealed that 24 questionnaires contained one or more items relevant to the construct and were comprehensive in addressing one or more problems.

In the UK sample, 23 questionnaires were deemed relevant, each addressing at least one of the commonly reported problems identified by study participants. The TSS questionnaire was the most comprehensive, covering five out of six problems (n=5/6). The TQ, THQ, and TFI followed, each addressing four out of six problems (n=4/6), though the problems varied among them. For the SA sample, 22 questionnaires were considered applicable. The TFI and TQ emerged as the most comprehensive, each covering four out of five identified problems (n=4/5). The THQ, TSS, STSS, TRQ, and SETMQ each addressed three of the five reported problems (n=3/5). Tables 6.4 and 6.5 present the comprehensiveness of the questionnaires for the UK and SA samples and figures 6.8 and 6.9 demonstrate tinnitus questionnaires that cover one or more problems reported by study samples.

Table 6.4 Tinnitus questionnaires which comprehensively addressed the problems identified by the UK sample.

No	Questionnaire/ (no. of total items)	% items relevant/ (no. of relevant items)	% comprehensiveness/ (no. of problems covered)
1	Tinnitus Questionnaire/ (52)	23% (12)	66.6% (n=4/6)
2	Mini Tinnitus Questionnaire/ (12)	25% (3)	33.3% (n=2/6)
3	Tinnitus Handicap Questionnaire/ (27)	15% (4)	66.6% (n=4/6)
4	Tinnitus Severity Scale/ (27)	40% (11)	83% (n=5/6)
5	Subjective Tinnitus Severity Scale/ (16)	25% (40)	50% (n=3/6)
6	Tinnitus Reaction Questionnaire/ (26)	11.5% (3)	33.3% (n=2/6)
7	Tinnitus Severity Index/ (12)	33.3% (4)	50% (n=3/6)
8	Tinnitus Coping Style Questionnaire/ (40)	2.5% (1)	16.7% (n=1/6)
9	Tinnitus Handicap Inventory/ (25)	12% (3)	33.3% (n=2/6)
10	International Tinnitus Inventory/ (8)	12% (1)	16.7% (n=1/6)
11	Tinnitus Catastrophizing Scale/ (13)	7.7% (1)	16.7% (n=1/6)
12	Tinnitus Vigilance and Awareness Questionnaire/ (18)	33% (6)	33.3% (n=2/6)
13	Tinnitus disability Index/ (7)	28.6% (2)	16.7% (n=1/6)
14	Self-Efficacy for Tinnitus Management Questionnaire/ (40)	10% (4)	16.7% (n=1/6)
15	Tinnitus Fear Avoidance Scale/ (14)	14.3% (2)	16.7% (n=1/6)
16	Tinnitus Functional Index/ (25)	28% (7)	66.6% (n=4/6)
17	Tinnitus Magnitude Index/ (3)	66% (2)	33.3% (n=2/6)
18	Tinnitus Primary Function Questionnaire/ (20)	30% (6)	33.3% (n=2/6)
19	Tinnitus Primary Function Questionnaire/ (12)	33% (4)	33.3% (n=2/6)
20	Tinnitus and Hearing Survey/ (10)	10% (1)	16.7% (n=1/6)
21	Skarzynski Tinnitus Scale/ (18)	5.5% (1)	16.7% (n=1/6)
22	FiveQ/ (5)	20% (1)	16.7% (n=1/6)
23	Tinnitus Impact Questionnaire/ (7)	14.2% (1)	16.7% (n=1/6)

Table 6.5 Tinnitus questionnaires which comprehensively addressed the problems identified by the SA sample.

No	Questionnaire/ (no. of total items)	% items relevant/ (no. of relevant items)	% comprehensiveness/ (no. of problems covered)
1	Tinnitus Questionnaire/ (52)	19.2% (10)	80% (n=4/5)
2	Mini Tinnitus Questionnaire/ (12)	16.6% (2)	40% (n=2/5)
3	Tinnitus Handicap Questionnaire/ (27)	11.1% (3)	60% (n=3/5)
4	Tinnitus Severity Scale/ (27)	29.6% (8)	60% (n=3/5)
5	Subjective Tinnitus Severity Scale/ (16)	18.75% (3)	60% (n=3/5)
6	Tinnitus Reaction Questionnaire/ (26)	11.5% (3)	60% (n=3/5)
7	Tinnitus Severity Index/ (12)	2.5% (3)	60% (n=3/5)
8	Tinnitus Handicap Inventory/ (25)	16.6% (2)	40% (n=2/5)
9	International Tinnitus Inventory/ (8)	12..5% (1)	20% (n=1/5)
10	Tinnitus Catastrophizing Scale/ (13)	7.7% (1)	20% (n=1/5)
11	Tinnitus Vigilance and Awareness Questionnaire/ (18)	11% (2)	20% (n=1/5)
12	Tinnitus disability Index/ (7)	14.3% (1)	20% (n=1/5)
13	Self-Efficacy for Tinnitus Management Questionnaire/ (40)	20% (8)	60% (n=3/5)
14	Tinnitus Functional Index/ (25)	32% (8)	80% (n=4/5)
15	Tinnitus Magnitude Index/ (3)	33% (1)	20% (n=1/5)
16	Tinnitus Primary Function Questionnaire/ (20)	25% (5)	20% (n=1/5)
17	Tinnitus Primary Function Questionnaire/ (12)	25% (3)	20% (n=1/5)
18	Tinnitus and Hearing Survey/ (10)	20% (2)	40% (n=2/5)
19	Skarzynski Tinnitus Scale/ (18)	11% (2)	40% (n=2/5)
20	Five Q/ (5)	40% (2)	40% (n=2/5)
21	Tinnitus Impact Questionnaire/ (7)	14.2% (1)	20% (n=1/5)
22	4 C Tinnitus Management Questionnaire/ (4)	25% (1)	20% (n=1/5)

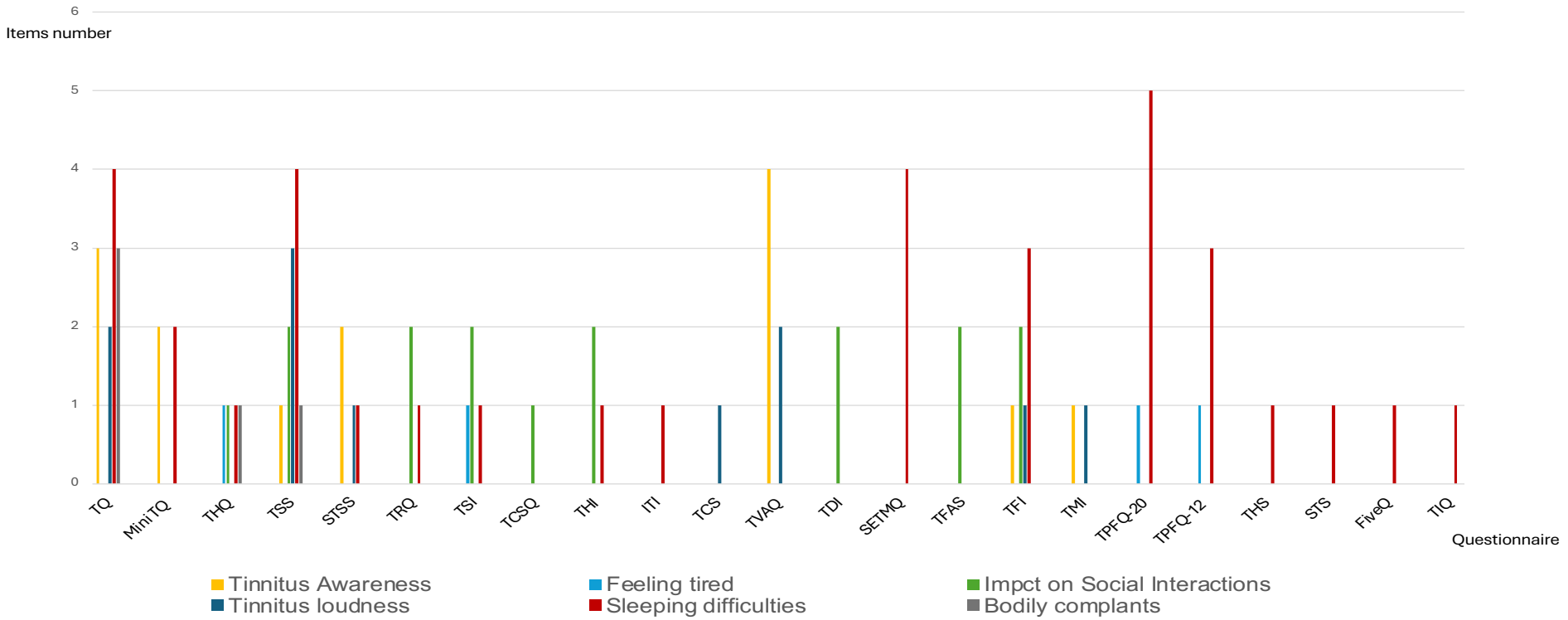


Figure 6.8 Coverage of reported problems by twenty-three questionnaires reported by UK participants. The x-axis lists the respective questionnaires while the y-axis indicates the number of items addressing each specific problem (*TQ: Tinnitus Questionnaire, Mini TQ: Mini Tinnitus Questionnaire, THQ: Tinnitus Handicap Questionnaire, TSS: Tinnitus Severity Scale, STSS: Subjective Tinnitus Severity Scale, TRQ: Tinnitus Reaction Questionnaire, Tinnitus Severity Index, Tinnitus coping Style Questionnaire, THI: Tinnitus Handicap Inventory, ITI: Tinnitus International Inventory, TCS, Tinnitus Catastrophizing Scale, TVAQ: Tinnitus Vigilance Awareness Questionnaire, TDI, Tinnitus Disability Index, SETMQ: Self-Efficacy for Tinnitus Management Questionnaire, TFAS: Tinnitus Fear Avoidance Scale, TFI: Tinnitus Functional Index, TMI, Tinnitus Magnitude Index, TPFQ: Tinnitus Primary Function Questionnaire, THS: Tinnitus and Hearing Survey, STS: Skarzynski Tinnitus Scale, TIC: Tinnitus Impact Questionnaire)*

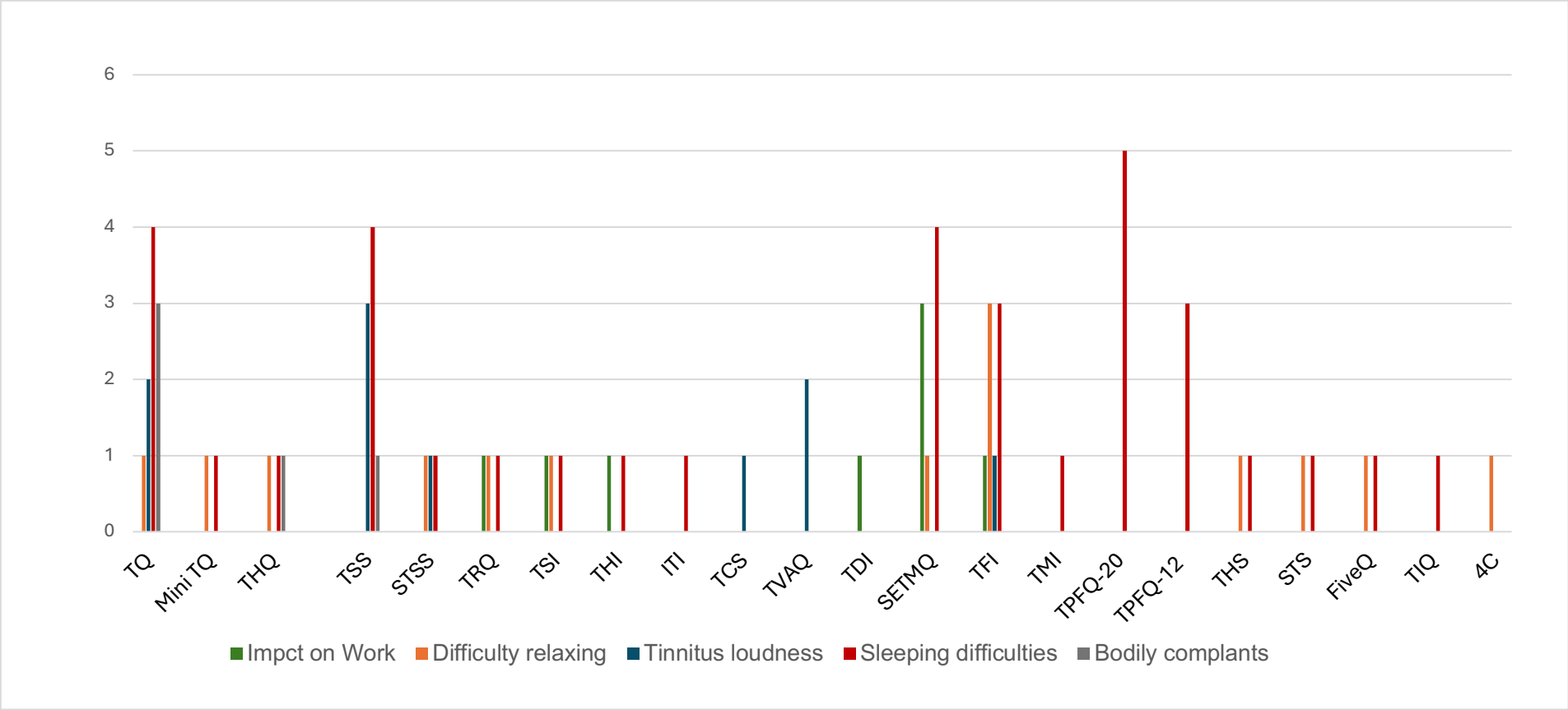


Figure 6.9 Coverage of reported problems by twenty-two questionnaires reported by SA participants. The x-axis lists the respective questionnaires while the y-axis indicates the number of items addressing each specific problem (*TQ: Tinnitus Questionnaire, Mini TQ: Mini Tinnitus Questionnaire, THQ: Tinnitus Handicap Questionnaire, TSS: Tinnitus Severity Scale, STSS: Subjective Tinnitus Severity Scale, TRQ: Tinnitus Reaction Questionnaire, Tinnitus Severity Index, Tinnitus coping Style Questionnaire, THI: Tinnitus Handicap Inventory, ITI: Tinnitus International Inventory, TCS, Tinnitus Catastrophizing Scale, TVAQ: Tinnitus Vigilance Awareness Questionnaire, TDI, Tinnitus Disability Index, SETMQ: Self-Efficacy for Tinnitus Management Questionnaire, TFI: Tinnitus Functional Index, TMI, Tinnitus Magnitude Index, TPFQ: Tinnitus Primary Function Questionnaire, THS: Tinnitus and Hearing Survey, STS: Skarzynski Tinnitus Scale, TIC: Tinnitus Impact Questionnaire)*

6.4 Discussion

The primary objective of this study was to identify common tinnitus associated problems reported by study participants and to evaluate the content validity of various tinnitus questionnaires based on these problems. The results revealed a broad spectrum of issues, which were categorised into three domains: physical health, level of independence, and the negative attributes of tinnitus sound.

Most reported problems fell within the physical health domain, including sleeping difficulties, bodily complaints, feeling tired, and difficulties relaxing. Sleeping difficulties and bodily complaints, such as dizziness and vomiting, were observed in both study samples, whereas feeling tired was more frequently reported in the UK sample, and difficulty relaxing was specific to the SA sample. Sleeping difficulties were particularly prominent, consistent with previous research (Brüggemann et al., 2016; Gallo et al., 2023; Hall et al., 2018a; Pierzycki et al., 2016; Watts et al., 2018). Hall et al. (2018a) identified sleep problems as the most common complaint among tinnitus patients, regardless of study design, and noted that patients with severe tinnitus reported poorer sleep outcomes. Moreover, tinnitus and sleep disturbances have a bidirectional relationship, where exacerbation of tinnitus can impair sleep, and poor sleep quality can worsen tinnitus (Milinski et al., 2022). This relationship is likely due to the overlap in brain regions involved in both processes, and disrupted sleep may hinder the brain's ability to habituate to tinnitus. Despite the provision of cochlear implants to some participants in the UK sample, sleep issues persisted, with some studies even advising against the use of cochlear implants in individuals with severe sleep disturbances (Pierzycki et al., 2016).

Still in the physical health domain, feeling tired was noted as a concern for UK participants, while SA participants primarily reported difficulty relaxing. Although related, these two experiences differ in nature: tiredness typically results from physical exertion or sleep

deprivation, whereas difficulty relaxing refers to an inability to achieve mental or physical calm, even in the absence of physical tiredness. Fatigue, or the pervasive feeling of tiredness, has been shown to contribute significantly to tinnitus-related disability (Dauman et al., 2017). Tinnitus-induced disablement refers to the significant impairment of daily functioning and quality of life, with persistent tinnitus leading to frustration and long-term suffering. Moreover, fatigue, which can manifest as both mental and physical exhaustion, is also linked to tinnitus severity (Turunen-Taheri et al., 2023). In a study by Turunen-Taheri et al. (2023), 67% of participants with severe tinnitus also reported high levels of mental fatigue, suggesting that mental fatigue exacerbates the impact of tinnitus. Also, severe mental fatigue is particularly common in patients with severe tinnitus, more so than in those with hearing loss alone, highlighting the need to address both auditory and mental health challenges in tinnitus management.

Difficulty relaxing, specific to the SA sample, could be a result of poor sleep, as these two issues share common physiological pathways. Tinnitus-induced difficulties in relaxation likely exacerbate sleep problems, contributing to a vicious cycle of worsening symptoms. These issues also impact the participants' work life; a factor associated with the level of independence domain.

The impact of tinnitus on socialisation, specifically reported in the UK sample, further highlights its effect on the level of independence domain. Tinnitus can impair individuals' ability to engage in social interactions, as the persistent nature of the sound and the cognitive demands it places on sufferers may lead to withdrawal from social activities. Participants in the UK sample expressed concerns about feeling socially isolated or unable to participate in social events due to the distraction or annoyance caused by their tinnitus.

Tinnitus loudness, often described as a negative attribute of the tinnitus sound, was reported in both study samples, with participants frequently using phrases like "it is too loud" in their

responses. The loudness of tinnitus has been shown to worsen sleep disturbances and negatively impact overall quality of life. It is one of the most commonly studied aspects of tinnitus, regardless of the presence of hearing loss (Hall et al., 2016; Rademaker et al., 2021). Rademaker et al. (2021) found that, based on patient preferences, tinnitus loudness is considered a key outcome in tinnitus therapy. A discrete choice experiment was conducted to examine patient priorities for tinnitus treatment outcomes (Rademaker et al., 2021). The study revealed that reducing tinnitus loudness was the most important outcome for patients, followed by improvements in sleep quality, tinnitus acceptance, and concentration. Interestingly, two distinct patient subgroups emerged, each with different priorities. The majority of patients prioritised loudness reduction along with other improvements, while a smaller group valued increased tinnitus acceptance and stable sleep quality over loudness reduction. Additionally, preferences were found to correlate with the severity of baseline tinnitus. These findings highlight the need for personalized approaches in tinnitus treatment and underscore the importance of incorporating patient preferences into both clinical trial design and therapeutic strategies. This research validates the reduction of tinnitus loudness as a core outcome in tinnitus trials and emphasizes the need for a more comprehensive, patient-centred approach in both research and treatment. While participants in the SA group considered the question of loudness less relevant, they still expressed its significant impact, highlighting the importance of using a mixed-methods approach to explore this issue.

Tinnitus awareness was more pronounced in the UK sample, which consisted predominantly of individuals with acquired hearing loss. Awareness is one of the commonly discussed factors in tinnitus research and it is a pillar in many theoretical models. However, most of the included models do not provide an explanation why the UK sample were so aware of their tinnitus, unlike the SA sample. The ecological model of tinnitus (Searchfield, 2014) offers a potential explanation, emphasising the interaction between the individual, environmental, and

social context in shaping tinnitus perception. The model suggests that neural plasticity and cognitive processes such as attention and memory influence tinnitus awareness, and that acquired hearing loss may lead to heightened tinnitus perception through these adaptive changes. Additionally, the complex relationship between tinnitus and hearing loss is further influenced by environmental and genetic factors, highlighting the need for further research to explore how these variables contribute to tinnitus awareness in different populations (Searchfield, 2014).

One key factor that could influence these findings is the type of hearing loss—whether congenital (present from birth) or acquired later in life. Individuals with congenital hearing loss may have developed adaptive coping mechanisms from a young age, and their experience of tinnitus might be more integrated with long-term adaptation to reduced auditory input. For them, tinnitus may not be as distressing, and they might report fewer psychological and physical health problems related to the condition, as they have likely developed strategies to manage both the sensory loss and tinnitus. In contrast, individuals with acquired hearing loss may experience a more abrupt change in their auditory perception, making the onset of tinnitus more acute and potentially more disruptive. This group may report a higher frequency of distress, anxiety, and difficulties in social and work environments because sudden sensory change often leads to greater emotional burden and adaptation challenges.

The second phase of the study assessed the content validity of 28 tinnitus questionnaires, revealing substantial variability in how effectively these tools addressed the problems reported by participants from the UK and Saudi Arabia. Notably, none of the questionnaires covered all the issues identified in either population, highlighting the necessity of using at least two instruments for a comprehensive assessment.

However, In the UK sample, the Tinnitus Severity Scale (TSS), developed by Sweetow and Levy in 1990, was the most comprehensive, capturing five out of six reported problems (figure 6.8). It evaluates tinnitus-related loudness, concentration difficulties, sleep disruptions, tinnitus duration, and the overall impact on quality of life. Following the TSS, the Tinnitus Questionnaire (TQ), the Tinnitus Functional Index (TFI), and the Tinnitus Handicap Questionnaire (THQ) each addressed four distinct issues. Specifically, the TFI targeted tinnitus awareness, impact on social interactions, tinnitus loudness, and sleep difficulties. The TQ addressed tinnitus awareness, loudness, sleep disturbances, and bodily complaints, while the THQ focused on tiredness, social interaction difficulties, sleep issues, and bodily complaints.

For the Saudi Arabian (SA) sample, the TFI, TQ emerged as the most comprehensive tools, each addressing four distinct issues (figure 6.9). The TFI covered work-related impact, relaxation difficulties, tinnitus loudness, and sleep disturbances. In comparison, the TQ addressed relaxation difficulties, tinnitus loudness, sleep disturbances, and bodily complaints.

One noteworthy finding from the current analysis is that the widely used THI, despite its popularity in the UK, addressed only two tinnitus-related issues in each sample. For the UK sample, it focused on social interaction difficulties, while in the SA group, it addressed work-related challenges and sleep disturbances. This highlights a potential limitation in the THI's capacity to comprehensively reflect the wide range of tinnitus impacts.

6.5 Conclusion

This study highlights the diverse range of problems experienced by individuals with tinnitus, with sleep disturbances, fatigue, and difficulties relaxing being prominent concerns across both study samples. Additionally, the impact of tinnitus on socialisation, particularly in the UK sample, underscores its broader effects on independence and mental well-being. These

issues have a significant impact on physical health, mental health, and daily functioning, underscoring the need for comprehensive approaches to tinnitus management that address both auditory and non-auditory symptoms. Further research is needed to explore the underlying mechanisms of these symptoms and their relationship with tinnitus awareness and severity across different populations.

Existing tinnitus questionnaires show variability and limitations, especially when used with diverse populations such as individuals who are deaf or have severe-to-profound hearing loss in the UK and SA; notably, no single instrument captures the full range of tinnitus-related issues identified in either sample. Therefore, there is a need for a comprehensive assessment tool that can more effectively address the diverse experiences and challenges associated with tinnitus in these populations.

Chapter 7: General discussion

The aim of this PhD was to explore the experience of tinnitus in two distinct populations of deaf and severely-to-profoundly hearing-impaired adults in the United Kingdom and Saudi Arabia. In addition, existing assessment tools were evaluated in light of the commonly reported challenges. To achieve these aims, the study began with a comprehensive review of existing literature on tinnitus, its assessment, and management strategies relevant to individuals with similar hearing loss. A mixed-methods approach was then employed to explore the lived experience of tinnitus, supported by two distinct qualitative methodologies, each designed to serve a specific analytical purpose and research question. This approach enabled the collection of rich, in-depth data from participants in both study samples.

To analyse the qualitative data, two complementary methods were employed: framework analysis and content analysis. Framework analysis provided a structured, transparent way to organise data according to pre-defined themes, ensuring consistency across participants. Content analysis allowed for the identification of unanticipated patterns and meanings within the data. The concurrent use of these two methods allowed for cross-validation of findings, enhancing the credibility and depth of the insights obtained. This methodological triangulation enriched the study's ability to capture both expected and emergent facets of the tinnitus experience.

The findings led to the identification of core issues commonly faced by these populations and facilitated the analysis of existing tinnitus questionnaires. As a result, the study proposed the most comprehensive tool for capturing the unique tinnitus-related problems reported by these groups, thus contributing to more effective management strategies. This approach aligns with the growing recognition of the need for patient-centred outcome measures in tinnitus research and clinical practice.

7.1 Study findings

The real-world experience of tinnitus in adults with severe-to-profound hearing loss remains underexplored, primarily due to limited empirical research in this area (Alzahrani et al., 2022). Most studies identified in the review focussed on cochlear implants, with tinnitus often investigated as a secondary concern, rather than examining the direct impact of tinnitus on individuals with severe hearing loss. Furthermore, existing tinnitus questionnaires have not been validated for use in deaf populations, making it challenging to accurately assess tinnitus severity and treatment outcomes in this group. Various treatment approaches, including medication, repetitive transcranial magnetic stimulation (rTMS), electrical promontory stimulation, and behavioural self-control therapy, have been explored, but these are reported in only a handful of studies. While cochlear implants and hearing aids are commonly investigated, tinnitus is typically considered a secondary outcome in implant studies, and the effectiveness of hearing aids in tinnitus management remains inconclusive, with a need for stronger evidence and more rigorous randomised controlled trials. Moving forward, there is a pressing need this is what to develop tailored tinnitus management for this population. The validation of assessment tools specifically designed for deaf populations is crucial to advancing effective tinnitus management. Additionally, future research should prioritise personalised treatment approaches to improve outcomes for this group. Hence, the understanding of tinnitus in adults with severe-to-profound hearing loss is limited, and future studies should aim to address the gaps in both assessment and treatment strategies to better support this population.

In Chapters 4 and 5, the lived experience of tinnitus was examined through a mixed methods approach. This approach was chosen due to its ability to provide a comprehensive understanding of the phenomenon for several key reasons. First, it allows for the validation of

findings between the quantitative data gathered from both quantitative tools, THI and DASS total scores with the qualitative insights from the semi-structured interviews. By integrating both data sources, I was able to cross-check and enrich our understanding of tinnitus. The combination of quantitative and qualitative data offered a fuller, more nuanced perspective on the challenges and experiences faced by individuals with tinnitus, capturing both measurable symptoms and the subjective, personal impact of the condition. Furthermore, the ability to analyse the quantitative and qualitative components independently provided valuable insights that could inform recommendations based on each method individually. The quantitative results offered a clear, objective measure of tinnitus severity, while the qualitative data illuminated the personal, lived experience, allowing for a more holistic view of the condition. Ultimately, the mixed methods approach proved to be the most suitable method for addressing the research questions and contributing to a deeper understanding of tinnitus in this population.

The use of semi-structured interviews enabled the application of two qualitative methods: framework analysis and content analysis. While both approaches analysed the same data set, they served complementary purposes. Framework analysis provided a structured, transparent way to organise data around pre-defined themes, ensuring consistency across participants. In contrast, content analysis allowed for identification of unanticipated patterns and meanings. This dual approach enriched the depth and credibility of the findings through methodological triangulation, though it required careful integration to maintain coherence. Overall, combining these methods offered a more comprehensive understanding of participants' lived experiences with tinnitus.

The findings revealed that while tinnitus manifests uniquely across individuals, its impact is often similarly disruptive—regardless of hearing status. Notably, tinnitus affects those who are D/deaf or have severe-to-profound hearing loss in ways comparable to individuals with

mild or moderate hearing loss, aligning with prior research (Watts et al., 2018; Colagrosso et al., 2019; Beukes et al., 2018).

Language and cultural context played a significant role in shaping participants' experiences. SSL is a naturally emerging, yet still evolving language, distinct from spoken Arabic. Despite recent improvements in media representation and access, SSL remains inconsistently standardised and lacks full institutional and legal recognition. Consequently, Deaf individuals in Saudi Arabia often face delayed language acquisition and limited opportunities for early intervention, affecting their ability to access healthcare and describe complex sensory experiences such as tinnitus. In contrast, BSL benefits from legal recognition, standardisation, and well-established educational and support infrastructures in the UK. Early exposure to BSL and structured interpreter services contribute to stronger Deaf identity and better access to healthcare services. These systemic differences may explain the greater use of medical and audiological support, including assistive devices, among UK participants.

An interesting and perhaps unexpected finding was the emergence of adaptive coping mechanisms among the Saudi Deaf participants. Many reported managing their tinnitus independently, without seeking medical advice. In particular, those who developed tinnitus at a younger age often exhibited more successful adaptation, suggesting that early onset may offer an opportunity for habituation (Beukes et al., 2018). While this was not the primary focus of the study, it raises a critical gap in current research: the impact of tinnitus in children with sensory impairments such as deafness. Children who are Deaf and experience tinnitus often go undiagnosed, in part because they may lack the language or awareness to articulate their symptoms. This represents a significant oversight in clinical practice. Several Saudi participants who were prelingually Deaf described encountering tinnitus during childhood, yet they received no formal diagnosis or support. Addressing this issue through early

screening, education, and parental awareness could help mitigate long-term emotional and psychological distress. This is supported by emerging evidence that early intervention improves outcomes (Hoare et al., 2024; Smith et al., 2019).

The study utilised DASS to assess associated psychological comorbidities. Considering psychological comorbidities is particularly important when evaluating individuals with tinnitus, especially those who are deaf or have severe-to-profound hearing loss. Assessing psychological well-being and providing referrals when necessary is crucial, as the relationship between deafness and psychological illness may be further intensified by the presence of tinnitus (Roze et al., 2020).

Assistive devices played a significant role in shaping the tinnitus experience among UK participants. Cochlear implants and hearing aids were reported to have both positive and negative effects. While some individuals experienced a reduction in tinnitus symptoms following cochlear implantation—suggesting a modulating or masking effect—others reported a worsening of symptoms. This variability underscores the complex relationship between hearing restoration technologies and tinnitus perception. It reinforces the need for individualised treatment plans that consider the multifactorial nature of tinnitus and the diverse responses to assistive devices.

Finally, the role of healthcare systems must be strengthened through better education, clinical awareness, and patient reassurance. Healthcare professionals should receive up-to-date training on tinnitus in the context of hearing loss, particularly among the Deaf community. Standardised screening protocols and culturally sensitive communication strategies should be implemented to ensure equitable access to care and support for all individuals experiencing tinnitus.

Moving forward in Chapter 6, the focus was to identify the problems reported by both study groups using established taxonomies, allowing for the mapping of these problems onto various tinnitus questionnaires. The underlying issue was that the total scores from the THI did not adequately reflect the complaints reported in interviews. While the THI is widely used in the general population, it has not been tested or validated in individuals who are deaf or have severe-to-profound hearing impairment. Therefore, the objective of this chapter was to identify key symptoms and experiences that could inform the development of a comprehensive assessment tool tailored to the needs of this population. By analysing the distinct tinnitus experiences from both groups, the chapter aimed to ensure the selection of an assessment tool that accurately captures the severity, impact, and variability of tinnitus across different types of deafness and assistive device usage. Ultimately, the goal was to provide a customised assessment framework that better reflects the diverse tinnitus experiences, improving clinical evaluation and informing potential treatment strategies.

This analysis revealed several problems common to the two sample groups, such as sleeping difficulties, tinnitus loudness, and bodily complaints. However, the presence of complaints unique to each group was a particularly interesting finding. For example, awareness of tinnitus emerged as a major problem for the UK sample, whereas the Saudi sample presented a different, yet equally important issue. Notably, some participants in the Saudi group, particularly those who had been deaf since birth, reported experiencing tinnitus from childhood. These individuals often experienced feelings of confusion and fear but never sought medical advice, likely due to a lack of awareness or understanding of the condition.

This study provides a novel contribution to the understanding of tinnitus within the Saudi community, offering valuable insights into how individuals perceive and respond to their condition. While tinnitus has been explored in various cultural contexts, there remains a

significant gap in research focusing on lived experiences in Saudi Arabia. The findings of this study begin to address that gap by shedding light on the unique ways participants interpret and manage their symptoms.

However, several limitations must be acknowledged. These include the relatively small sample size and the absence of prior studies on the lived experiences of individuals with tinnitus and variable degree of hearing loss in the Saudi community. Unlike other populations where tinnitus has been explored more extensively, there is a clear lack of comparable research within this specific cultural context. This makes it difficult to fully understand whether the experiences reported are culturally unique or share commonalities with global patterns.

Moreover, the lack of prior lived experience studies limits opportunities for comparative analysis. This gap highlights the importance of culturally grounded research to better understand how Saudi participants feel or express their tinnitus in comparison to other communities. Despite these limitations, the study offers important implications for both theoretical frameworks and clinical practice. It underscores the need for culturally sensitive interventions and lays a foundation for future research that can explore this complex issue in greater depth.

The analysis of existing tinnitus questionnaires reveals a significant gap in comprehensively capturing the full spectrum of issues reported by patients. to overcome this issue, two proposed approaches to enhance Tinnitus Assessment in the given population. The first approach is to administer two or more validated tinnitus questionnaires simultaneously. For instance, combining the TQ with TFI, or TSS with THQ, allows for a more comprehensive evaluation of the multifaceted impact of tinnitus. This method captures emotional, functional, and social domains, providing a broader understanding of the patient’s condition. However, it

is crucial that each instrument is validated within the specific target population to ensure accuracy and relevance. Additionally, when instruments are used across different linguistic or cultural groups, careful translation and cultural adaptation are essential to maintain validity and reliability (Hall et al., 2018c; Streiner & Kottner, 2014; Terwee et al., 2018).

The second approach involves modifying a single established questionnaire to better fit the needs of the study population. This method offers practical advantages, such as tailoring assessments to specific populations and reducing participant burden by limiting the number of items. However, modifications must be approached with scientific rigor to preserve the psychometric integrity of the original instrument. Modifying an established questionnaire—whether by adding, removing, or rewording items—requires careful methodological consideration. Existing instruments have typically undergone extensive validation to ensure their reliability, validity, and sensitivity to change. Altering such instruments without a structured adaptation process risks compromising their measurement properties.

To maintain psychometric robustness, adaptation should involve the following key steps (Humble, 2020; Mokkink et al., 2019; Rattray & Jones, 2007; Song et al., 2015):

1. Content Validation: Engage an expert panel to review the modified items, ensuring they remain conceptually consistent with the original constructs.

2. Pilot Testing: Administer the modified questionnaire to a small sample from the target population to assess clarity, relevance, and comprehensibility.

3. Psychometric Re-Evaluation: Conduct reliability testing (e.g., internal consistency, test-retest reliability) and validation studies (e.g., construct and criterion validity).

To sum up, while the modification of existing questionnaires is a valid approach to enhancing tinnitus assessment, it must be supported by methodologically sound adaptation processes to

ensure continued reliability and validity of the instrument. Concurrent use of multiple validated questionnaires remains a practical and effective method for achieving broad tinnitus assessment in diverse populations. Both approaches have their merits and can be considered based on the specific needs and constraints of the study population.

7.2 Study implication

The findings of this study have significant implications for how tinnitus is understood and managed among adults who are deaf or have severe-to-profound hearing impairments.

It is crucial to recognise that deaf individuals can experience tinnitus, even if they do not explicitly report it. Due to the nature of their hearing loss and unique communication needs, tinnitus may present in more subtle or less conventional ways. Nevertheless, its secondary effects-such as sleep disturbances, reduced work performance, and overall diminished quality of life-can be just as significant. These findings highlight the need for a more inclusive and nuanced understanding of tinnitus, one that considers its varied manifestations across different populations. Deaf individuals must be offered appropriate and tailored care. While cochlear implants can be beneficial in restoring hearing and may alleviate tinnitus in some cases, they do not always resolve related issues such as sleep disruption. Therefore, a more holistic and comprehensive approach to tinnitus management is essential for individuals with hearing loss, aligning with the guiding principles of person-centred care in adult hearing rehabilitation, which emphasize understanding individual needs, collaborative goal setting, and supporting overall quality of life through tailored interventions care as recommended by the Practice Guidance provided by the British Society of Audiology (BSA, 2025).

7.3 Future recommendation

Based on the study's findings, several key recommendations can be made for clinical practice and future research. First, proactive tinnitus inquiry in Deaf and severe-to-profound hearing loss populations

Clinicians should routinely and proactively inquire about tinnitus in individuals who are deaf or have severe-to-profound hearing loss. Many individuals may be unaware of or underreport their symptoms, underscoring the importance of direct inquiry during clinical assessments. When tinnitus is identified, clinicians should ensure patients are informed about the full range of management strategies, including counselling, cognitive behavioural therapy, and the potential benefits of hearing aids or cochlear implants, all of which can improve quality of life even in cases of profound hearing loss (Miller & Tseng, 2024; BSA, 2025).

Secondly, addressing communication barriers: use of interpreters and accessible materials

It is crucial to address communication barriers in the assessment and management of tinnitus for deaf and severely hearing-impaired individuals. Many faces significant language barriers in healthcare, especially when discussing complex symptoms like tinnitus. Providing qualified interpreters, sign language materials, and accessible resources such as speech-to-text services or captioning ensures that patients fully understand their condition and management options. This approach improves care quality and empowers patients to participate in treatment decisions, reducing the risk of misdiagnosis or inadequate (BSA, 2025).

Moreover, specialized counselling should be offered to individuals considering or receiving cochlear implants. This counselling must provide comprehensive information about both the potential benefits and limitations of the device, particularly regarding tinnitus. Special

attention should be given to managing expectations and addressing associated issues such as sleep disturbances (Pierzycki et al., 2016).

Finally, optimization and validation of tinnitus assessment tools. There is a clear need to optimize and validate assessment tools that can fully capture the impact of tinnitus in adults who are deaf or have severe-to-profound hearing loss. Existing tools may not adequately reflect the unique experiences and challenges faced by this population, highlighting the importance of developing or adapting instruments that are sensitive to their needs.

These recommendations are grounded in current evidence and aim to improve clinical outcomes and guide future research for individuals with significant hearing loss and tinnitus.

7.4 Conclusion

This PhD thesis substantially enriches our understanding of tinnitus in adults with severe-to-profound hearing impairment, including those who are deaf. By exploring the unique experiences and challenges faced by this population, the research has brought to light the high prevalence and significant impact of tinnitus in these individuals-factors that are often under-recognized in clinical practice.

The findings underscore the complexity of managing tinnitus alongside severe hearing loss, particularly in the context of communication barriers and the need for tailored assessment and intervention strategies. Through a comprehensive examination of clinical, communicative, and psychosocial aspects, this work highlights the importance of a holistic, patient-centred approach to care.

Overall, the thesis provides a strong foundation for advancing both clinical practice and future research. It encourages the development of more sensitive assessment tools and effective management options, ultimately aiming to improve the quality of care and life for adults with severe-to-profound hearing loss who experience tinnitus.

Appendices

Appendix 1 Study ethical approval

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
Research Ethics Committee
Faculty Hub
Room E41, E Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH
Email: FMHS-ResearchEthics@nottingham.ac.uk

14 June 2021

Lama Alzahrani
PhD in Otorhinolaryngology
Hearing Sciences, Clinical Neuroscience
NIHR Nottingham Biomedical Research Centre (BRC)
Ropewalk House,113 The Ropewalk
Nottingham
NG1 5DU

Dear Ms Alzahrani

Ethics Reference No: FMHS 254-0521**– please always quote**	
Study Title: Experience of tinnitus in adults who are Deaf or have severe-profound hearing loss adults.	
Location of Study: Nottingham and KAU King Abdulaziz University, Kingdom of Saudi Arabia	
Chief Investigator/Supervisor: Derek Hoare, Associate Professor in Hearing Sciences, NIHR BRC, School of Medicine.	
Lead Investigators/student: Lama Alzahrani, PhD in Otorhinolaryngology, School of Medicine	
Other Key Investigators/Collaborators: Magdalena Sereda, Senior Research Fellow, Hearing Sciences, NIHR BRC, School of Medicine	
Proposed Start Date: 01/06/2021	**Proposed End Date:** 30/12/2022

The Committee considered this application at its meeting on 21 May 2021 and the following documents were received:

- FMHS REC Application form and supporting documents version 1.0: 10.05.2021

These have been reviewed and are satisfactory and the research project has been given a favourable ethics opinion.

Please submit copies of letters of permission from the University of King Abdulaziz to place posters and advertise your study in the University when these are available so they can be noted to file. This must be completed before recruitment of human participants commences.

Please note that this favourable ethics opinion has been given on the understanding that:

1. All appropriate ethical requirements and regulatory permissions are respected and followed in accordance with all local laws of the country in which the study is being conducted and those required by the host organisation/s involved.
2. The research project will adhere to ICH E6 (R2) Good Clinical Practice (GCP) which is the international ethical, scientific, and practical standard to which all clinical research is conducted.
3. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
4. The Chair is informed of any serious or unexpected adverse event.
5. An End of Project Progress Report is completed and submitted to FMHS REC within six months after the study has finished (Please request a form).

Yours sincerely

Dr John Williams, Associate Professor
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix 2 Participant consent form

University of Nottingham
UK | CHINA | MALAYSIA

Participant Consent Form
Final version 2.0: 10.05.2021

Title of Study: Experience of tinnitus in Deaf/ severe-profound hearing loss adults**.**

REC ref: FMHS 254-0521

Name of Researchers: Lama Alzahrani, Derek Hoare, Magdalena Sereda

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number 1 dated 08.05.21 for the above study which is attached 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 and without any negative consequences on my course of study. ☐
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 the interview/ will be audio recorded using a digital device and that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I understand that information about me recorded during the study will be made anonymous before it is stored. It will be uploaded into a secure database on the University of Nottingham OneDrive. ☐
6. **Optional:** I agree that my anonymous research data will be stored and used to support other research in the future and shared with other researchers including those working outside the University.
7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 3 Invitation letters, Arabic and English

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
School of Medicine
NIHR Nottingham Biomedical Research Centre
Ropewalk House
113 The Ropewalk
Nottingham, NG1 5D

Invitation

Dear ():

We are recruiting for a study that is looking at how people who are Deaf or have a severe or profound hearing loss experience tinnitus. The Information sheet for this study is attached. We are contacting you because you have indicated that you are interested in taking part in tinnitus research. Please read carefully to see if it is suitable for you and to consider whether you would like to participate.

Summary of participant requirements:

We are looking for people who are

- 18 years of age or over
- Deaf or have a severe or profound hearing loss
- Are willing to take part in an interview and complete some short health questionnaires

For further details please refer to the information sheet.

If you have any questions or queries regarding the study or would like to be considered for participation, please don't hesitate to contact the student researcher Lama Alzahrani on lama.alzahrani@nottingham.ac.uk

Many thanks,

Lama Alzahrani
lama.alzahrani@nottingham.ac.uk

رسالة دعوة

العزيز ():

نحن نوظف لدراسة تبحث في كيفية إصابة الأشخاص الصم أو الذين يعانون من فقدان سمع حاد أو عميق بطنين الأذن. مرفق طيه ورقة المعلومات الخاصة بهذه الدراسة. نتواصل معك لأنك أشرت إلى أنك مهتم بالمشاركة في أبحاث طنين الأذن. يرجى القراءة بعناية لمعرفة ما إذا كانت مناسبة لك وللنظر فيما إذا كنت ترغب في المشاركة.

ملخص متطلبات المشترك:

نحن نبحث عن أشخاص:

- يبلغ من العمر 18 عامًا أو أكثر
- الصمم أو يعاني من ضعف شديد أو شديد في السمع
- مستعدون للمشاركة في مقابلة وإكمال بعض الاستبيانات الصحية القصيرة

لمزيد من التفاصيل يرجى الرجوع إلى ورقة المعلومات.

إذا كان لديك أي أسئلة أو استفسارات بخصوص الدراسة أو ترغب في المشاركة في الدراسة، من فضلك لا تتردد في الاتصال بالباحثة الطالبة لما الزهراني على lama.alzahrani@nottingham.ac.uk

شكرا جزيلا،

لمي الزهراني

lama.alzahrani@nottingham.ac.uk

Appendix 4 Tinnitus Handicap Inventory, English version

Appendix 2

NHS
National Institute for
Health Research

Tinnitus Handicap Inventory

Project title:

Investigators:

ID Code:

Date:

PURPOSE: This scale measures the severity and impact of your tinnitus.

INSTRUCTIONS: Please circle the answer which best applies to you (either 'yes', 'no' or 'sometimes'). Do not skip any questions.

Please answer the questions as accurately as possible as this is very important to the outcome of this research.

The information you provide in this questionnaire will be treated confidentially.

Version 1 18 December 2013

NIHR Nottingham Biomedical Research Centre | Ropewalk House, 113 The Ropewalk, Nottingham, NG1 5DU
Tel: 0115 823 2600 | Fax: 0115 823 2618 | Web: http://hearing.nihr.ac.uk/

1.	Because of your tinnitus is it difficult for you to concentrate?	Yes	No	Sometimes
2.	Does the loudness of your tinnitus make it difficult for you to hear people?	Yes	No	Sometimes
3.	Does your tinnitus make you angry?	Yes	No	Sometimes
4.	Does your tinnitus make you confused?	Yes	No	Sometimes
5.	Because of your tinnitus are you desperate?	Yes	No	Sometimes
6.	Do you complain a great deal about your tinnitus?	Yes	No	Sometimes
7.	Because of your tinnitus do you have trouble falling asleep at night?	Yes	No	Sometimes
8.	Do you feel as though you cannot escape from your tinnitus?	Yes	No	Sometimes
9.	Does your tinnitus interfere with your ability to enjoy social activities (such as going out to dinner or to the cinema)?	Yes	No	Sometimes
10.	Because of your tinnitus do you feel frustrated?	Yes	No	Sometimes
11.	Because of your tinnitus do you feel that you have a terrible disease?	Yes	No	Sometimes
12.	Does your tinnitus make it difficult to enjoy life?	Yes	No	Sometimes
13.	Does your tinnitus interfere with your job or household responsibilities?	Yes	No	Sometimes
14.	Because of your tinnitus do you find that you are often irritable?	Yes	No	Sometimes
15.	Because of your tinnitus is it difficult for you to read?	Yes	No	Sometimes
16.	Does your tinnitus make you upset?	Yes	No	Sometimes
17.	Do you feel that your tinnitus has placed stress on your relationships with members of your family and/or friends?	Yes	No	Sometimes
18.	Do you find it difficult to focus your attention away from your tinnitus and on to other things?	Yes	No	Sometimes
19.	Do you feel that you have no control over your tinnitus?	Yes	No	Sometimes
20.	Because of your tinnitus do you often feel tired?	Yes	No	Sometimes
21.	Because of your tinnitus do you feel depressed?	Yes	No	Sometimes
22.	Does your tinnitus make you feel anxious?	Yes	No	Sometimes
23.	Do you feel you can no longer cope with your tinnitus?	Yes	No	Sometimes
24.	Does your tinnitus get worse when you are under stress?	Yes	No	Sometimes
25.	Does your tinnitus make you feel insecure?	Yes	No	Sometimes

For office use only:

PROVENANCE:

McCombe A, Baguley D, Coles R, et al Guidelines for the grading of tinnitus severity: the results of a working group commissioned by the British Association of Otolaryngologists - Head and Neck Surgeons.1999. 2001 Clin Otolaryngol 26, 388-393

Newman CW, Jacobson GP and SpitzerJB. Development of the Tinnitus Handicap Inventory. 1996. Arch otolaryngol Head Neck Surg. 122 143-148.

Newman CW, Sandridge SA and Jacobson GP. Psychometric adequacy of the Tinnitus Handicap Inventory (THI) for evaluating treatment outcome. 1998. J Am Acad Audiol 9: 153-160

SCORING:

Total THI score:
(number of 'yes' responses x 4) + (number of 'sometimes' responses x 2)

INTERPRETATION:
The range of scores is 0-100.

0 – 6: Slight or No Handicap (Grade 1)
18 – 36: Mild Handicap (Grade 2)
38 – 56: Moderate Handicap (Grade 3)
58 – 76: Severe Handicap (Grade 4)
78 – 100: Catastrophic Handicap (Grade 5)

A minimal clinically meaningful change is 20 points.

Appendix 5 Tinnitus Handicap Inventory, Arabic version

Supplemental Appendix 1 (available online only). Arabic THI.

استبيان حول اعاقة طنين الاذن

استبيان رقم:..... التاريخ:.....

ان الهدف من هذا الاستبيان هو تحديد المشاكل التي يتسبب بها طنين الاذن لديك. اختر "نعم" او "احيانا" او "كلا" لكل سؤال في المكان المناسب. نرجو منك ألا تتخطى اي سؤال. Xعبر وضع علامة

1. هل يصعب عليك التركيز بسبب الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
2. هل يؤثر مستوى الطنين على سمعك للناس؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
3. هل تشعر بالغضب بسبب الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
4. هل تشعر بالارباك بسبب الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
5. هل تشعر باليأس بسبب الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
6. هل تشكو كثيرا للناس حواليك من الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
7. هل تعاني من صعوبة بالغفو ليلا" بسبب الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
8. هل تشعر انه ليس بإمكانك الهروب من الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
9. هل يحدّ الطنين من قدرتك على الأستمتاع بالانشطة الأجتماعيّة مثل الخروج لتناول العشاء أو الذهاب ألى السينما؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
10. هل تشعر بالاحباط نتيجة الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
11. هل تشعر بأنّ لديك مرض خطير بسبب الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
12. هل يصعب عليك الاستمتاع بالحياة نتيجة الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
13. هل يتداخل الطنين مع عملك او مسؤولياتك المنزلية؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
14. هل تشعر غالبا انك سريع الانفعال بسبب الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
15. هل تصعب عليك القراءة بسبب الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
16. هل يجعلك الطنين مستاءً ؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
17. هل يسبّب الطنين توتّر في علاقاتك مع بقيّة أفراد عائلتك و أصدقائك؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
18. هل تجد انه من الصعب عليك تركيز انتباهك على امور اخرى بعيدا عن الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
19. هل تشعر انه ليس لديك اي سيطرة على الطنين ؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
20. هل تشعر غالبا" بالتعب بسبب الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
21. هل تشعر بالكآبة بسبب الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
22. هل يدفعك الطنين الى القلق؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
23. هل تشعر بأنّك لم تعد قادر على التعايش مع الطنين؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
24. هل يسوء الطنين تحت الضغط؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)
25. هل يشعرك الطنين بعدم الأمان؟	□ نعم (4)	□ أحيانا (2)	□ كلا (0)

Appendix 6 Depression, Anxiety, Stress Scale, English version

DASS21

Name: Date:

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree or a good part of time
3 Applied to me very much or most of the time

1 (s)	I found it hard to wind down	0	1	2	3
2 (a)	I was aware of dryness of my mouth	0	1	2	3
3 (d)	I couldn't seem to experience any positive feeling at all	0	1	2	3
4 (a)	I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5 (d)	I found it difficult to work up the initiative to do things	0	1	2	3
6 (s)	I tended to over-react to situations	0	1	2	3
7 (a)	I experienced trembling (e.g. in the hands)	0	1	2	3
8 (s)	I felt that I was using a lot of nervous energy	0	1	2	3
9 (a)	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10 (d)	I felt that I had nothing to look forward to	0	1	2	3
11 (s)	I found myself getting agitated	0	1	2	3
12 (s)	I found it difficult to relax	0	1	2	3
13 (d)	I felt down-hearted and blue	0	1	2	3
14 (s)	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15 (a)	I felt I was close to panic	0	1	2	3
16 (d)	I was unable to become enthusiastic about anything	0	1	2	3
17 (d)	I felt I wasn't worth much as a person	0	1	2	3
18 (s)	I felt that I was rather touchy	0	1	2	3
19 (a)	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
20 (a)	I felt scared without any good reason	0	1	2	3
21 (d)	I felt that life was meaningless	0	1	2	3

DASS-21 Scoring Instructions

The DASS-21 should not be used to replace a face to face clinical interview. If you are experiencing significant emotional difficulties you should contact your GP for a referral to a qualified professional.

Depression, Anxiety and Stress Scale - 21 Items (DASS-21)

The Depression, Anxiety and Stress Scale - 21 Items (DASS-21) is a set of three self-report scales designed to measure the emotional states of depression, anxiety and stress.

Each of the three DASS-21 scales contains 7 items, divided into subscales with similar content. The depression scale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest / involvement, anhedonia and inertia. The anxiety scale assesses autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The stress scale is sensitive to levels of chronic non-specific arousal. It assesses difficulty relaxing, nervous arousal, and being easily upset / agitated, irritable / over-reactive and impatient. Scores for depression, anxiety and stress are calculated by summing the scores for the relevant items.

The DASS-21 is based on a dimensional rather than a categorical conception of psychological disorder. The assumption on which the DASS-21 development was based (and which was confirmed by the research data) is that the differences between the depression, anxiety and the stress experienced by normal subjects and clinical populations are essentially differences of degree. The DASS-21 therefore has no direct implications for the allocation of patients to discrete diagnostic categories postulated in classificatory systems such as the DSM and ICD.

Recommended cut-off scores for conventional severity labels (normal, moderate, severe) are as follows:

NB Scores on the DASS-21 will need to be multiplied by 2 to calculate the final score.

	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely Severe	28+	20+	34+

Lovibond, S.H. & Lovibond, P.F. (1995). Manual for the Depression Anxiety & Stress Scales. (2nd Ed.)Sydney: Psychology Foundation.

Appendix 7 Depression, Anxiety, Stress Scale, Arabic version

Arabic DASS21

اسم:_____ التاريخ:_____

اقرأ كل من النصوص التالية ثم ضع دائرة حول الرقم ٠،١،٢ أو ٣ الذي يبين درجة انطباق هذا الشعور عليك في الأسبوع الماضي. لا يوجد إجابات صحيحة أو خاطئة. لا تقضي وقتاً طويلاً في أي منها.

استعمل التقديرات التالية:

٠ لا ينطبق عليّ بتاتاً
١ ينطبق عليّ بعض الشيء أو قليلاً من الأوقات
٢ ينطبق عليّ بدرجة ملحوظة أو بعض الأوقات
٣ ينطبق عليّ كثيراً جداً، أو معظم الأوقات

١	وجدت صعوبة في الاسترخاء والراحة	٠	١	٢	٣
٢	شعرت بجفاف في حلقي	٠	١	٢	٣
٣	لم يبدو لي أن بإمكاني الإحساس بمشاعر إيجابية على الإطلاق	٠	١	٢	٣
٤	شعرت بصعوبة في التنفس (شدة التنفس السريع، اللهثان بدون القيام بمجهود جسدي مثلاً)	٠	١	٢	٣
٥	وجدت صعوبة في أخذ المبادرة بعمل الأشياء	٠	١	٢	٣
٦	كنت أميل إلى ردة فعل مفرطة للظروف والأحداث	٠	١	٢	٣
٧	شعرت برجفة (باليدين مثلاُ)	٠	١	٢	٣
٨	شعرت بأنني أستهلك الكثير في الطاقة العصبية (شعرت بأنني أستهلك الكثير من قدرتي على تحمل التوتر العصبي)	٠	١	٢	٣
٩	كنت خائفاً من مواقف قد أفقد فيها السيطرة على أعصابي واسبب إحراجاً لنفسي	٠	١	٢	٣
١٠	شعرت بأن ليس لدي أي شيء أتطلع إليه	٠	١	٢	٣
١١	شعرت بأنني مضطرب ومنزعج	٠	١	٢	٣
١٢	أجد صعوبة في الاسترخاء	٠	١	٢	٣
١٣	شعرت بالحزن والغم	٠	١	٢	٣
١٤	كنت لا أستطع تحمل أي شيء يحول بيني وبين ما أرغب في القيام به	٠	١	٢	٣
١٥	شعرت بأنني على وشك الوقوع في حالة من الرعب المفاجئ بدون سبب	٠	١	٢	٣
١٦	فقدت الشعور بالحماس لأي شيء	٠	١	٢	٣
١٧	شعرت بأن قيمتي قليلة كشخص	٠	١	٢	٣
١٨	شعرت بأنني أميل إلى الغيظ بسرعة	٠	١	٢	٣
١٩	شعرت بضربات قلبي بدون مجهود جسدي (زيادة في معدل الدقات، أو غياب دقة قلب، مثلاً)	٠	١	٢	٣
٢٠	شعرت بالخوف بدون أي سبب وجيه	٠	١	٢	٣
٢١	شعرت بأن الحياة ليس لها معنى	٠	١	٢	٣

Appendix 8 Demographic sheet and interview guide

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
School of Medicine
NIHR Nottingham Biomedical Research Centre
Ropewalk House
113 The Ropewalk
Nottingham, NG1 5DU

Demographics Questionnaire

Participant ID

1. **Demographics**

a. Age _____ years

b. Employment Employed (1) / Unemployed (2) / Retired (3)

c. Gender _____ Male (1) / Female (2)

d. Ethnicity _____

2. **Hearing loss**

a. Onset of hearing loss. (1) Congenital (2) acquired

b. Cause of hearing loss

_____

c. Mode of communication

_____

d. Use of any hearing devices. (1) Hearing aids (2) Cochlear implant (3) none

Hearing aid use	**Right**	**Left**

Comments _____

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
School of Medicine
NIHR Nottingham Biomedical Research Centre
Ropewalk House
113 The Ropewalk
Nottingham, NG1 5DU

Interview Guide

Introduction:

I would like to thank you for coming today and taking part in this study. This is totally voluntary, and you are welcome to withdraw at any time. I will be asking you a few questions about your tinnitus experience and the impact that tinnitus has on your daily life activity.

Interview outlines:

First: Tinnitus Characteristics:

1. Onset: when was the first time you experienced (heard) tinnitus? Can you elaborate more on the incidence?

   _____

2. Characteristics: can you describe the sound?

   _____

3. Site of tinnitus: where do you hear the sound? One ear (right or left or both), head?

   _____

4. What do you think the cause of your tinnitus?

   _____

5. Frequency: Do you hear it all the time or does it come and go? Probe situations where it is more or less noticeable/a problem

   _____

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
School of Medicine
NIHR Nottingham Biomedical Research Centre
Ropewalk House
113 The Ropewalk
Nottingham, NG1 5DU

7. Are there any factors that make you tinnitus less noticeable, less a problem?

8. Are there strategies you use to cope with tinnitus? Support from others?

9. Have you accessed healthcare for your tinnitus, what, did it help?

10. What do you think would be useful in terms of healthcare provision?

11. What do you think would be useful in terms of future research?

Thank you☺

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
School of Medicine
NIHR Nottingham Biomedical Research Centre
Ropewalk House
113 The Ropewalk
Nottingham, NG1 5DU

Tinnitus Impact:

1. How to do you feel your tinnitus affected you personally? How did it affect your daily activities, examples?

a) Sleep

b) Work

c) Family time

d) Isolation

6. Are there any factors that make your tinnitus more noticeable, or more of a problem? for example, stress, work level

Appendix 9 The thematic framework

Tinnitus experience in deaf and severe-profound hearing-impaired adults in SA and UK.

Code	Description	*Example quotes*
Theme 1: Characteristics of tinnitus This theme focuses on the participants' initial experience with tinnitus, including its characteristics and their perceptions of its cause. It also explores the outcome of their tinnitus episode.		
Tinnitus onset	Participants in the study reflect on their initial encounter with tinnitus. Some individuals experienced tinnitus prior to their exact discovery of their hearing loss, while others lived with tinnitus without being aware of its presence.	*"I always have tinnitus and thought it is normal thing. Until one day, I read in the Newspaper, and I asked my mum do you have it and she said no. maybe when I was 15 years."* ***Case 2*** *"it was no long after I became deaf and it started gradually and I kept hearing the noises but I couldn't understand it"* ***case 4***
Tinnitus sound quality	Participants attempt to describe the characteristics of their tinnitus sound.	*"It is one buzzing sound that become louder if I am stressed"* ***case 7*** *"Multiple sound, always changing such as a lorry reversing, the insistent beep-beep, also, a rushing sound like being underwater"* ***case 13***
Lateralization	The location of tinnitus	*"Both side but if implant is on, the tinnitus in the right disappear and remain the one in the left"* ***case 10*** *"It can be off the sides"* ***case 8***
Cause	Participants provide their opinions on the potential causes of their tinnitus.	*"I guess because I was exposing myself to loud music when I was young"* ***case 8*** *"I really don't know but may because I am profoundly deaf. It has worsened because there is no real sound to offset it"* ***case 13***
Temporal quality of tinnitus	Referred to as the duration of tinnitus episodes	*"It can last few minutes and can lasts for hrs"* ***case 9***
Frequency	The frequency of tinnitus episodes per day or week or month.	*"It might be twice a week but then it might not happen for six months"* ***case 1*** *"It presents all the time but nosier and louder in the morning"* ***case 4***
Associated symptoms	Participants are asked to describe any associated symptoms that occur during episodes of tinnitus.	*"Headache which I had to lie in bed"* ***case 13***
Natural history	The participants share their experiences regarding the onset of their tinnitus and any changes they have observed in its characteristics over time.	*"It became noticeable since I started to be aware of it"* ***case 8*** *"My tinnitus started quite low level but now it hovers between loud and extremely low"* ***case 10***

Discriminating it from external sounds	Certain participants within this group share their ability to distinguish between tinnitus and external sounds.	
Theme 2: Tinnitus impact: Participants in this thematic discussion describe the personal impact of tinnitus and on their overall quality of life, including its effects on sleep, work, and family time. They discuss how tinnitus often led to avoidance and isolation. The discussion also explores the factors that influenced tinnitus, such as triggers that increased or decreased its severity. Finally, participants share the coping strategies they developed over the years to manage their tinnitus.		
Factors affecting tinnitus	**Increase:** Stress of any cause such as tired, lack of sleep, sick. Loud noise or noisy environment Quite Nothing as it always present **Decrease:** Resting Nothing as it goes by itself. **Trigger:** Tinnitus was not present, and something occurred and trigger tinnitus such as CI surgery.	*"My tinnitus goes most of the time in the background, I am not aware of it unless something spiking like loud noise or not properly fitted"* ***case 3*** *Not from my experience make it worse than now"* ***case 2*** *"Nothing although the lockdown help me a little bit by staying at home and doing work remotely"* ***case 2*** *"I don't really know but I think resting and sleeping in my own room help"* ***case 11*** *"I think there is a connection between when I had general anaesthetic when I was twenty-nine and when I had the implant because each time I had a general anaesthetic the tinnitus has got worse* *"* ***case 2*** *"Being anxious can trigger my tinnitus or make it worse"* ***case 4***
Emotional impact	Participants share their personal experiences and reflections on the impact of tinnitus on their lives.	*"Tinnitus is part of me now, but used to drive me crazy"* ***case 5*** *"Massive impact….I can't mask it because I can't use equipment out there like white noise and sound maskers so the biggest impact it has on the quality of my life is my sleep on my social and my work life and my own enjoyment of things because it's exhausting…* ***case 2*** *"I think emotionally tiring, it is very distracting"* ***case 11***
Impact on QoL	Sleep Work Family Isolation	<u>Sleep</u> *"it was disruptive like my sleep that I had to attend sleeping classes and take Melatonin"* ***case 2*** <u>Work</u>

		"No, I deal with it, I can't enjoy myself, but U can keep going" ***case 2*** <u>Family</u> *"I become resilient to attend any family event because of the noise"* ***case 4*** <u>Isolation:</u> *"No, I don't want to stay in a quite a place"* ***case 8*** *"A bit, because I need to concentrate on one person and my implant off and I got tinnitus in the same time"* ***case 9***
Coping strategies	Participants discuss the coping strategies they develop or adopt to manage their tinnitus. in general, learning to ignore it or cope were an example of these mechanisms.	*"it was very distressing in the beginning but I did get used to it and you learn to cope"* ***case 3*** *"Working can help me in ignoring my tinnitus"* ***case 11*** *"I learn myself to distract myself such as watching TV or doing anything that require sound rather than sitting in silent or ignore it".* *"Also screaming and shouting can help temporarily"* ***case 13***
Theme 3: Healthcare provision to treat tinnitus. This theme explores whether participants sought help from healthcare providers to treat their tinnitus and the effectiveness of the assistance received.		
Seeker for help or never	Participants in this category discuss whether they sought assistance or chose not to, citing reasons that they later mention.	*"I asked and they were very helpful but cannot find any strategy for my tinnitus"* ***case 5*** *"No, because I think I can manage"* ***case 9*** *"I never asked because I just assumed nothing can done about it"* ***case 11***
Negative experience to healthcare providers	Participants recount a negative experience when seeking tinnitus treatment due to healthcare providers' lack of awareness about their responsibilities in this area.	"I am very disappointed from GP coz they are uneducated enough and they don't know where to signpost people for support" **case 2** *"It depresses me really because they just say you have tinnitus, and you have to got to get with it"* **case 3** *"Some of the advice they give are unrealistic such as listening to white noise and it will go away" "I was referred to a counselling clinic for tinnitus and she said she have no ideas"* ***case 13***

Appendix 10 problems identified by stakeholders among study participants

	Scoping review		SA population		UK population		
PHYSICAL HEALTH							
Physical health problems							
Sleep difficulties	trouble falling asl	wake up	impact on sleep		waking up	trouble falling	sleep difficulti
Bodily complaints	dizziness		vomiting	dizziness			
Difficulties relaxing							
Feeling tired			tired		exhaustion	tiredness	
Pain	headache	muscle pain	pain in the ear	headache	headache		
Loss of appetite							
PSYCHOLOGICAL							
Functional difficulties due to tinnitus							
Negative effects on hearing							
Concentration difficulties			distraction or concentration problems		concentration problems		
Cognitive difficuties							
Ability to ingnore							
Tinnitus-related distress							
Annoyance			annoyance		annoyance		
Worries/concerns							
Irritable					irritable		
Distress from bodily sensations							
Fear			fear		fear of silence		
Frustration					frustration		
Negative thoughts about tinnitus							
Loss of control	lack of control/loss of control						
Change in sense of self							
Suicidal thoughts							
Loss of peace							
Irrational beliefs							
Mood states							
General distress					mental health		
Anxiety	anxiety						
Depressive symptoms	depression						
Lack of joy							
Anger							
LEVEL OF INDEPENDENCE/MOBILITY SOCIAL RELATIONSHIPS ENVIRONMENT							
Health related quality of life							
Quality of life associated with tinnitus							
Negative impact on activities							
Negative impact on social life			isolation		isolation	impact on soc	withdrawal fr
Negative impact on work activities			impact on work		impact on work		
Negative impact on individual activities					avoidance	avoiding quiet	
Difficulties coping							
Negative impact on relationships			impact on family		impact on family		
Lack of support from family and friends			lack of understanding by friends				
Sexual difficulties							
NEGATIVE ATTRIBUTES OF TINNITUS SOUND							
Tinnitus loudness	loudness of tinnitus		loudness		loudness		
Tinnitus awareness			cannot ignore		aware/ constat sound present all the time		
Tinnitus intrusiveness					intrusiveness		
Tinnitus pitch							
Tinnitus location							
Tinnitus unpleasentness							

Appendix 11 An example of questionnaire (Tinnitus Questionnaire) items coding among stakeholders and final decision

First: items agreement	Tinnitus Awareness				Feeling tired			Impct on Social			Tinnitus loudnes			Sleeping difficulti				odily complan			Impct on Work			fficulty relaxi		
Q1/ Tinnitus Questionnaire/ Hallam 1988 (52 items, 3 subscales)(response rate … and	MS	RSD	LA	DH	MS	RSD	LA	MS	RSD	LA	MS	RSD	LA	MS	RSD	LA	DH	MS	RSD	LA	MS	RSD	LA	MS	RSD	LA
1. I can sometimes ignore the noises even when they are there	3	3	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
2. I am unable to enjoy listening to music because of noises (AP)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
3. It's unfair that I have to suffer with my noises (ED)	1	2	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	2	1
4. I wake up more in the night becaue of my noises (SD)	1	1	1		1	2	1	1	1	1	1	1	1	3	3	3		1	1	1	1	1	1	1	1	1
5. I am aware of the noises from the moment I get up to the moment I sleep (IN	3	3	3		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
6. Your attitude to the noise makes no difference to how it affects you	1	2	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
7. Most of the time the noises are fairly quite (IN)	1	1	1		1	1	1	1	1	1	3	3	1	1	1	1		1	1	1	1	1	1	1	1	1
8. I worry that the noises will give me a nervous breakdown (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
9. Because of the noises I have difficulty in telling where sounds are coming from (AP)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
10. The way the noises sound is really unpleasant (IN)	1	2	1		1	1	1	2	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
11. I feel I can never get away from the noises (IN)	2	2	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
12. Because of the noises I wake up earlier in the morning (SD)	1	1	1		1	2	1	1	1	1	1	1	1	3	3	3		1	1	1	1	1	1	1	1	1
13. I worry weather I will be able to put up with this problem for ever (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
14. Because of the noises it is more difficult to listen to several people at once (AP)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
15. THE NOISES ARE loud most of the time (IN)	1	1	1		1	1	1	2	1	1	3	3	3	1	1	1		1	1	1	1	1	1	1	1	1
16. Because of the noises I worry that there is something seriously wrong with my body (ED	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		2	2	2	1	1	1	1	1	1
17. If the noises continue my life will not be worth living (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
18. I have lost some my confidence because of the noises (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
19. I wish someone understand what this problem is like (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
20. The noises distract me whatever I am doing (ED)	1	2	1		1	1	1	3	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	2	1
21. There is very little one can do to cope with the noises (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
22. The noises sometimes give me a pain in the ear or head (SM)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		3	3	3	1	1	1	1	1	1
23. When I feel low and pessimistic the noise seems worse.	1	2	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
24. I am more irritable with my family and friends because of the noises (ED	1	1	1		1	1	1	1	3	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
25. Because of the noises I have tension in the muscles of my head and neck (SM)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		3	3	3	1	1	1	1	1	1
26. Because of the noises other people's voices sound distorted to me (AP)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
27. It will be dreadful if these noises never go away (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
28. I worry that the noises might damage my physical health (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	2	1	1	1	1	1	1	
29. The noise seems to go right through my head (SM)	1	2	1		1	1	1	2	1	1	1	1	1	1	1	1		2	1	2	1	1	1	1	1	1
30. Almost all my problems are caused by these noises (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
31. Sleep is my main problem (SD)	1	1	1		1	2	1	1	1	1	1	1	1	3	3	3		1	1	1	1	1	1	1	1	1
32. It's the way you think about the noise - NOT the noise itself which makes you upset.	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
33. I have more difficulty following a conversation because of the noises (AP)	1	1			1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
34. I find it harder to relax because of the noises (SM)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	3	3	3
"35. My noises are often so bad that I cannot ignore them (IN)"	2	3	1	3	1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
36. It takes me longer to get to sleep because of the noises (SD)	1	1	1		1	2	1	1	1	1	1	1	1	3	3	1		1	1	1	1	1	1	1	1	1
37. I sometimes get very angry when I think about having the noises (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
38. I find it harder to use the telephone because of the noises (AP)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
39. I am more liable to feel low because of the noises (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
40. I am able to forget about the noises when I am doing something interesting	1	2	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
41. Because of the noises life seems to be getting on top of me (ED)	2	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
42. I have always been sensitive about trouble with my ears.	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
43. I often think about whether the noises will ever go away (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
44. I can imagine coping with the noises (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
45. The noises never 'let up' (IN)	2	2	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
46. A stronger person might be better at accepting this problem.	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
47. I am a victim of my noises (ED)	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
48. The noises have affected my concentration.	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
49. The noises are one of those problems in life you have to live with.	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	1	1
50. Because of the noises I am unable to enjoy the radio or television (AP)	1	1	1		1	1	1	1	1	1	1	1		1	1			1	1	1	1	1	1	1	1	
51. The noises sometimes produce a bad headache.	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1		3	3	3	1	1	1	1	1	1
52. I have always been a light sleeper.	1	1	1		1	2	1	1	1	1	1	1	1	2	3	1	1	1	1	1	1	1	1	1	1	1

Seconnd: relevance final decision	Tinnitus Aware	Feeling tired	Impct on Social	Tinnitus loudne	Sleeping difficu	Bodily complan	Impct on Work	Difficulty relaxing
1. I can sometimes ignore the noises ev	TRUE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
2. I am unable to enjoy listening to mu	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
3. It's unfair that I have to suffer with n	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
4. I wake up more in the night becaue o	FALSE	FALSE	FALSE	FALSE	TRUE	FALSE	FALSE	FALSE
5. I am aware of the noises from the mo	TRUE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
6. Your attitude to the noise makes no	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
7. Most of the time the noises are fairly	FALSE	FALSE	FALSE	TRUE	FALSE	FALSE	FALSE	FALSE
8. I worry that the noises will give me a	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
9. Because of the noises I have difficult	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
10. The way the noises sound is really	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
11. I feel I can never get away from the	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
12. Because of the noises I wake up earl	FALSE	FALSE	FALSE	FALSE	TRUE	FALSE	FALSE	FALSE
13. I worry weather I will be able to put	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
14. Because of the noises it is more diff	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
15. THE NOISES ARE loud most of th	FALSE	FALSE	FALSE	TRUE	FALSE	FALSE	FALSE	FALSE
16. Because of the noises I worry that th	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
17. If the noises continue my life will n	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
18. I have lost some my confidence bec	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
19. I wish someone understand what thi	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
20. The noises distract me whatever I ar	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
21. There is very little one can do to co	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
22. The noises sometimes give me a pa	FALSE	FALSE	FALSE	FALSE	FALSE	TRUE	FALSE	FALSE
23. When I feel low and pessimistic the	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
24. I am more irritable with my family	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
25. Because of the noises I have tension	FALSE	FALSE	FALSE	FALSE	FALSE	TRUE	FALSE	FALSE
26. Because of the noises other people's	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
27. It will be dreadful if these noises ne	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
28. I worry that the noises might damag	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
29. The noise seems to go right through	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
30. Almost all my problems are caused	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
31. Sleep is my main problem (SD)	FALSE	FALSE	FALSE	FALSE	TRUE	FALSE	FALSE	FALSE
32. It's the way you think about the noi	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
33. I have more difficulty following a c	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
34. I find it harder to relax because of th	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	TRUE
"35. My noises are often so bad that I c	TRUE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
36. It takes me longer to get to sleep be	FALSE	FALSE	FALSE	FALSE	TRUE	FALSE	FALSE	FALSE
37. I sometimes get very angry when I t	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
38. I find it harder to use the telephone	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
39. I am more liable to feel low because	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
40. I am able to forget about the noises	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
41. Because of the noises life seems to	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
42. I have always been sensitive about t	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
43. I often think about whether the nois	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
44. I can imagine coping with the noise	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
45. The noises never 'let up' (IN)	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
46. A stronger person might be better at	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
47. I am a victim of my noises (ED)	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
48. The noises have affected my concen	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
49. The noises are one of those problem	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
50. Because of the noises I am unable to	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE
51. The noises sometimes produce a ba	FALSE	FALSE	FALSE	FALSE	FALSE	TRUE	FALSE	FALSE
52. I have always been a light sleeper.	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE	FALSE

References:

Alamri, A. A. (2024). The reality and obstacles of teaching Saudi Arabian Sign Language (SASL) to hearing students in regular schools: Alshams Private School as a model. *Frontiers in Education*, *9*. https://doi.org/10.3389/feduc.2024.1245983

Alanazi, A. A. (2024). Tinnitus prevalence, associated characteristics, and treatment patterns among adults in Saudi Arabia. *Audiology Research, 14*(5), 760–777. https://doi.org/10.3390/audiolres14050064

Alasim, K. N. (2021). Recognition and comprehension of multiple-meaning words: Examining a vocabulary intervention with hard of hearing students. *American Annals of the Deaf, 166*(3), 262–283. https://doi.org/10.1353/aad.2021.0030

Almazroua, A. M., Alsughayer, L., Ababtain, R., Al-Shawi, Y., & Hagr, A. A. (2020). The association between consanguineous marriage and offspring with congenital hearing loss. *Annals of Saudi Medicine, 40*(6), 456–461. https://doi.org/10.5144/0256-4947.2020.456

Almusawi, H., Alasim, K., BinAli, S., & Alherz, M. (2021). Disparities in health literacy during the COVID-19 pandemic between the hearing and deaf communities. *Research in Developmental Disabilities, 119*. https://doi.org/10.1016/j.ridd.2021.104089

Alqarny, M., Assiri, A. M., Alshehri, A., Alharbi, S. M., Alshahrani, E. H., Alessa, H., & Alghubishi, S. A. (2021). Patterns and correlations of hearing loss among adolescents, adults, and elderly in Saudi Arabia: A retrospective study. *Cureus*. https://doi.org/10.7759/cureus.13913

Alsanosi, A. A. (2011). Impact of tinnitus on the quality of life among Saudi patients. *Saudi Medical Journal, 32*(12). https://pubmed.ncbi.nlm.nih.gov/22159383/

Altamimi, H. S., & Alsager, H. N. (2023). Argument Structure and Word Order in Saudi Sign Language. *Journal of Language Teaching and Research*, *14*(1), 203–214. https://doi.org/10.17507/jltr.1401.21

Alofi, A. S., Clark, M. D., & Marchut, A. E. (2019). Life Stories of Saudi Deaf Individuals.

Psychology, *10*(11), 1506–1525.
https://doi.org/10.4236/psych.2019.1011099

Amoodi, H., Abualross, O., Meer, N., & Alharbi, N. A. (2023). Prevalence and types of otological symptoms presenting in COVID-19 patients in Jeddah, Saudi Arabia: A questionnaire-based study. *Cureus*.
https://doi.org/10.7759/cureus.42042

Alzahrani, L., Sereda, M., Salles Chamouton, C., Haider, H., Dewey, R. S., & Hoare, D. J. (2022). Experience of tinnitus in adults who have severe-to-profound hearing loss: A scoping review. *Frontiers in Neurology, 13*, 1004059.
https://doi.org/10.3389/fneur.2022.1004059

Alzahrani, M. A., Aldajani, N. F., & Alghamdi, S. A. (2021). Guidelines for cochlear implantation in Saudi Arabia. *Saudi Medical Journal, 42*(12), 1265–1271.
https://doi.org/10.15537/smj.2021.42.12.20210262

American Speech-Language-Hearing Association. (1993). *Definitions of communication disorders and variations* [Relevant position statement]. https://www.asha.org/policy/rp1993-00208/

B

Baguley, D., McFerran, D., & Hall, D. (2013). Tinnitus. *The Lancet, 382*(9904), 1600 1607. https://doi.org/10.1016/S0140-6736(13)60142-7

Barake, R., Rizk, S. A., Ziade, G., Zaytoun, G., & Bassim, M. (2016). Adaptation of the Arabic version of the tinnitus handicap inventory. *Otolaryngology - Head and Neck Surgery (United States), 154*(3), 508–512.
https://doi.org/10.1177/0194599815621551

Barker, A. B., Leighton, P., & Ferguson, M. A. (2017). Coping together with hearing loss: a qualitative meta-synthesis of the psychosocial experiences of people with hearing loss and their communication partners. *International Journal of Audiology, 56*(5), 297–305.
https://doi.org/10.1080/14992027.2017.1286695

Barnett, S. (2002). *Communication with Deaf and Hard-of-hearing People: A Guide for Medical Education*.

Bartlett, E. L. (2013). The organization and physiology of the auditory thalamus and its role in processing acoustic features important for speech perception. *Brain and Language, 126*(1), 29–48. https://doi.org/10.1016/j.bandl.2013.03.003

Beck, A. T., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry, 4*(6), 561–571. https://doi.org/10.1001/archpsyc.1961.01710120031004

Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, *2*, 8–14. https://doi.org/10.1016/j.npls.2016.01.001

Beukes, E. W., Manchaiah, V., Valien, T. E., Baguley, D. M., Allen, P. M., & Andersson, G. (2018). Positive experiences related to living with tinnitus: A cross-sectional survey. *Clinical Otolaryngology, 43*(2), 489–495. https://doi.org/10.1111/coa.13002

Beukes, E., Ulep, A. J., Eubank, T., & Manchaiah, V. (2021). The impact of covid-19 and the pandemic on tinnitus: A systematic review. *Journal of Clinical Medicine, 10*(13). MDPI. https://doi.org/10.3390/jcm10132763

Bhatt, J. M., Bhattacharyya, N., & Lin, H. W. (2017). Relationships between tinnitus and the prevalence of anxiety and depression. *Laryngoscope, 127*(2), 466–469. https://doi.org/10.1002/lary.26107

Bisogno, A., Scarpa, A., Di Girolamo, S., De Luca, P., Cassandro, C., Viola, P., Ricciardiello, F., Greco, A., De Vincentiis, M., Ralli, M., & Di Stadio, A. (2021). Hearing loss and cognitive impairment: Epidemiology, common pathophysiological findings, and treatment considerations. *Life, 11*(10). https://doi.org/10.3390/life11101102

Biswas, R., Lugo, A., Akeroyd, M. A., Schlee, W., Gallus, S., & Hall, D. A. (2021). Tinnitus prevalence in Europe: a multi-country cross-sectional population study. https://doi.org/10.1016/j

Blazer, D. G., Domnitz, S., & Liverman, C. T. (2016). *Hearing health care for adults: Priorities for improving access and affordability*. National Academies Press. https://doi.org/10.17226/23446

Bohne, B. A., & Harding, G. W. E. (2008). Cochlear Anatomy.

Bowling, A. (2014). *Research methods in health: Investigating health and health services* (4th ed.). McGraw-Hill/Open University Press.

Boothroyd, A. (2007). Adult Aural Rehabilitation: What Is It and Does It Work? *Trends in Amplification, 11*(2), 63–71. https://doi.org/10.1177/1084713807301073

Bordeynik-Cohen, M., Sperber, M., Ebbers, L., Messika-Gold, N., Krohs, C., Koffler-Brill, T., Noy, Y., Elkon, R., Nothwang, H. G., & Avraham, K. B. (2023). Shared and organ-specific gene-expression programs during the development of the cochlea and the superior olivary complex. *RNA Biology, 20*(1), 629–640. https://doi.org/10.1080/15476286.2023.2247628

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

British Society of Audiology (2021). *Practice Guidance: Tinnitus in Adults*. Available https://www.thebsa.org.uk/wp-content/uploads/2023/10/OD104-95-BSA-practice-guidance-Tinnitus-in-adults-Publication-Nov-2021-1.pdf

British Sign Language Act 2022. (2022). Retrieved from https://www.legislation.gov.uk/ukpga/2022/34/contents

British Deaf Association. (2022). *BSL Act Now!*. Retrieved from https://bda.org.uk/bsl-act-now/

British Society of Audiology. (2024). *Guiding principles of person-centred care in adult hearing rehabilitation*. British Society of Audiology. Available from: https://www.thebsa.org.uk/wp-content/uploads/2024/10/Guiding-Principles-of-Person-Centred-Care-in-Adult-Hearing-Rehabilitation-2024.pdf

Brüggemann, P., Szczepek, A. J., Rose, M., McKenna, L., Olze, H., & Mazurek, B. (2016). Impact of multiple factors on the degree of tinnitus distress. *Frontiers in Human Neuroscience, 10*. https://doi.org/10.3389/fnhum.2016.00341

Charles Liberman, M. (2020). Hidden hearing loss: Primary neural degeneration in the noise damaged and aging cochlea. *Acoustical Science and Technology*, *41*(1), 59–62. https://doi.org/10.1250/ast.41.59

Charrois, T. L. (2015). Systematic reviews: What do you need to know to get started? *Canadian Journal of Hospital Pharmacy, 68*(2). https://doi.org/10.4212/cjhp.v68i2.1440

Cima, R. F. F., Crombez, G., & Vlaeyen, J. W. S. (2011). *Catastrophizing and fear of tinnitus predict quality of life in patients with chronic tinnitus* 10.1097/AUD.0b013e31821106dd

Cima, R. F., Maes, I. H., Joore, M. A., Scheyen, D. J., El Refaie, A., Baguley, D. M., Anteunis, L. J., van Breukelen, G. J., & Vlaeyen, J. W. (2012). Specialised treatment based on cognitive behaviour therapy versus usual care for tinnitus: A randomised controlled trial. *The Lancet*, *379*.

10.1016/S0140-6736(12)60469-3

Cima, R. F. F., van Breukelen, G., & Vlaeyen, J. W. S. (2018). Tinnitus-related fear: Mediating the effects of a cognitive behavioural specialised tinnitus treatment. *Hearing Research, 358*, 86-97. https://doi.org/10.1016/j.heares.2017.10.003

Cima, R. F. F., Mazurek, B., Haider, H., Kikidis, D., Lapira, A., Noreña, A., & Hoare, D. J. (2019). A multidisciplinary European guideline for tinnitus: diagnostics, assessment, and treatment. In *HNO* (Vol. 67, pp. 10–42). Springer Verlag. https://doi.org/10.1007/s00106-019-0633-7

Cohen, D. J., & Crabtree, B. F. (2008). Evaluative criteria for qualitative research in health care: Controversies and recommendations. *Annals of Family Medicine, 6*(4), 331-339. https://doi.org/10.1370/afm.818

Colagrosso, E. M. G., Fournier, P., Fitzpatrick, E. M., & Hébert, S. (2019). A Qualitative Study on Factors Modulating Tinnitus Experience. *Ear and Hearing, 40*(3), 636–644. https://doi.org/10.1097/AUD.0000000000000642

Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches* (2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. (2011). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Centres for Disease Control and Prevention (CDC). National Centre for Health Statistics (NCHS). (2021). *National Health and Nutrition Examination Survey Data (2017–March 2020)*. Hyattsville, MD: U.S. Department of Health and Human Services. https://wwwn.cdc.gov/nchs/nhanes/

Dauman, N., Erlandsson, S. I., Albarracin, D., & Dauman, R. (2017). Exploring tinnitus induced disablement by persistent frustration in aging individuals: A grounded theory study. *Frontiers in Aging Neuroscience*, *9*(AUG). https://doi.org/10.3389/fnagi.2017.00272

da Costa, S., van der Zwaag, W., Marques, J. P., Frackowiak, R. S. J., Clarke, S., & Saenz, M. (2011). Human primary auditory cortex follows the shape of Heschl's Gyrus. *Journal of Neuroscience, 31*(40), 14067–14075. https://doi.org/10.1523/JNEUROSCI.2000-11.2011

Davies, C. & M. Fisher. (2018). Understanding research paradigms. In *JARNA* (Vol. 21).

Dawadi, S., Shrestha, S., & Giri, R. A. (2021). Mixed-methods research: A discussion on its types, challenges, and criticisms. *Journal of Practical Studies in Education*, 2(2), 25–36. https://doi.org/10.46809/jpse.v2i2.20

Davis, A., & El Rafaie, A. (2000). Epidemiology of tinnitus. In R. Tyler (Ed.), *Tinnitus handbook* (pp. 1–23). Singular.

Dawes, P., Newall, J., Stockdale, D., & Baguley, D. M. (2020). Natural history of tinnitus in adults: A cross-sectional and longitudinal analysis. *BMJ Open, 10*(12). https://doi.org/10.1136/bmjopen-2020-041290

Denton, A. J., Finberg, A., Ashman, P. E., Bencie, N. B., Scaglione, T., Kuzbyt, B., Telischi, F. F., Mittal, R., & Eshraghi, A. A. (2021). Implications of Transcranial Magnetic Stimulation as a Treatment Modality for Tinnitus. *International Journal of Environmental Research and Public Health, 18*(4), https://doi.org/10.3390/jcm10225422

De Ridder, D., Schlee, W., Vanneste, S., Londero, A., Weisz, N., Kleinjung, T., Shekhawat, G. S., Elgoyhen, A. B., Song, J. J., Andersson, G., Adhia, D., de Azevedo, A. A., Baguley, D. M., Biesinger, E., Binetti, A. C., Del Bo, L., Cederroth, C. R., Cima, R., Eggermont, J. J., … Langguth, B. (2021). Tinnitus and tinnitus disorder: Theoretical and operational definitions (an international multidisciplinary proposal). In *Progress in Brain Research* (Vol. 260, pp. 1–25). Elsevier B.V. https://doi.org/10.1016/bs.pbr.2020.12.002

Degen CV, Mikuteit M, Niewolik J, Schröder D, Vahldiek K, Mücke U, Heinemann S, Müller F, Behrens GMN, Klawonn F, Dopfer-Jablonka A and Steffens S (2022) Self-reported Tinnitus and Vertigo or Dizziness in a Cohort of Adult Long COVID Patients.Front. Neurol. 13: 884002.
doi: 10.3389/fneur.2022.884002

Deklerck, A. N., Debacker, J. M., Keppler, H., & Dhooge, I. J. M. (2020). Identifying non

otologic risk factors for tinnitus: A systematic review. *Clinical Otolaryngology, 45*(5), 775–787.

https://doi.org/10.1111/coa.13592

Deniz, B., Boz, C., Kara, E., Deniz, R., Oruç, Y., Acar, M., Yılmaz, Y. Z., & Ataş, A. (2022). Direct health expenditure analysis related to hearing loss in individuals using hearing aids and cochlear implants. *Turkish archives of otorhinolaryngology, 60*(3), 142–148.

https://doi.org/10.4274/tao.2022.2022-4-3

Devocht, E. M. J., Janssen, M. A. L., Chalupper, J., Stokroos, R. J., Kingma, H., & George, E. L. J. (2020). Self-assessment of unilateral and bimodal cochlear implant experiences in daily life. *PLoS ONE, 15*(12 December).

https://doi.org/10.1371/journal.pone.0242871

Di Guilmi, M. N., Boero, L. E., Castagna, V. C., Rodríguez-Contreras, A., Wedemeyer, C., Gómez-Casati, M. E., & Elgoyhen, A. B. (2019). Strengthening of the efferent olivocochlear system leads to synaptic dysfunction and tonotopy disruption of a central auditory nucleus. *Journal of Neuroscience, 39*(36), 7037–7048.

https://doi.org/10.1523/JNEUROSCI.2536-18.2019

Di Nardo, W., Cantore, I., Cianfrone, F., Melillo, P., Scorpecci, A., Paludetti, G., et al. (2007). Tinnitus modifications after cochlear implantation. European Archives of Oto-Rhino-Laryngology, 264, 1145–1149.

https://doi.org/10.1007/s00405-007-0352-7

Di Nardo, W., Cianfrone, F., Scorpecci, A., Cantore, I., Giannantonio, S., Paludetti, G., et al. (2009). Transtympanic electrical stimulation for immediate and long-term tinnitus suppression. International Tinnitus Journal, 15, 100–106.

Dixon, P. R., Crowson, M., Shipp, D., Smilsky, K., Lin, V. Y., Le, T., et al. (2020). Predicting reduced tinnitus burden after cochlear implantation in adults. Otology & Neurotology, 41, 196–201.

https://doi.org/10.1097/MAO.0000000000002481

Dodd, S., Gorst, S. L., Young, A., Lucas, S. W., & Williamson, P. R. (2023). Patient participation impacts outcome domain selection in core outcome sets for research: an updated systematic review. *Journal of Clinical Epidemiology*, *158*, 127–133. https://doi.org/10.1016/j.jclinepi.2023.03.022

Durazzo, T. C., Meyerhoff, D. J., & Nixon, S. J. (2010). Chronic cigarette smoking: Implications for neurocognition and brain neurobiology. In *International Journal of Environmental Research and Public Health* (Vol. 7, Issue 10, pp. 3760–3790). MDPI. https://doi.org/10.3390/ijerph7103760

Eggermont, J. J., & Kral, A. (2016). Somatic memory and gain increase as preconditions for tinnitus: Insights from congenital deafness. *Hearing Research*, *333*, 37–48. https://doi.org/10.1016/j.heares.2015.12.018

Elgoyhen, A. B., & Langguth, B. (2010). Pharmacological approaches to the treatment of tinnitus. *Drug Discovery Today*, *15*(7–8), 300–305. https://doi.org/10.1016/j.drudis.2009.11.003

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107–115. https://doi.org/10.1111/j.1365-2648.2007.04569.x

Erlandsson, S. I. M., Lundin, L., & Dauman, N. (2020a). The Experience of Tinnitus and Its Interaction With Unique Life Histories—Life Events, Trauma and Inner Resources Narrated by Patients With Tinnitus. *Frontiers in Psychiatry*, *11*. https://doi.org/10.3389/fpsyt.2020.00136

Evans, C., Mellor-Clark, J., Margison, F., et al. (2000). CORE: Clinical Outcomes in Routine Evaluation. J Ment Health, 9, 247–255.

Fackrell, K., & Hoare, D. (2014). Questionnaires to measure tinnitus severity. *ENT and Audiology News*.

Fackrell, K., Hall, D. A., Barry, J. G., & Hoare, D. J. (2018). Performance of the Tinnitus Functional Index as a diagnostic instrument in a UK clinical population. *Hearing Research*, *358*, 74–85. https://doi.org/10.1016/j.heares.2017.10.016

Fackrell, K., Stratmann, L., Gronlund, T. A., & Hoare, D. J. (2019). Top ten hyperacusis research priorities in the UK. *The Lancet*, *393*(10170), 404–405. https://doi.org/10.1016/S0140-6736(18)32616-3

Farinetti, A., Ben Gharbia, D., Mancini, J., Roman, S., Nicollas, R., & Triglia, J. M. (2014). Cochlear implant complications in 403 patients: Comparative study of adults and children and review of the literature. *European Annals of Otorhinolaryngology, Head and Neck Diseases*, *131*(3), 177–182. https://doi.org/10.1016/j.anorl.2013.05.005

Ferguson, M., & Henshaw, H. (2015). Computer and internet interventions to optimize listening and learning for people with hearing loss: Accessibility, use, and adherence. *American Journal of Audiology*, *24*(3), 338–343. https://doi.org/10.1044/2015_AJA-14-0090

Fettiplace, R. (2023). Cochlear tonotopy from proteins to perception. *BioEssays*, *45*(8). John Wiley and Sons Inc. https://doi.org/10.1002/bies.202300058

Fettiplace, R., & Kim, K. X. (2014). The physiology of mechanoelectrical transduction channels in hearing. *Physiological Reviews*, *94*(3), 951–986. American Physiological Society. https://doi.org/10.1152/physrev.00038.2013

Folmer, R. L., & Griest, S. E. (2000). Tinnitus and insomnia. *American Journal of Otolaryngology - Head and Neck Medicine and Surgery*, *21*(5), 287–293. https://doi.org/10.1053/ajot.2000.9871

Fukuda, Y. (1998). The AllHear cochlear implant and tinnitus. International Tinnitus Journal, 4, 159–161.

Fuller, T., Cima, R., Langguth, B., Mazurek, B., Vlaeyen, J. W. S., & Hoare, D. J. (2020). Cognitive behavioural therapy for tinnitus. *Cochrane Database of Systematic Reviews*, *2020*(1). https://doi.org/10.1002/14651858.CD012614.pub2

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, *13*(1). https://doi.org/10.1186/1471-2288-13-117

Galazyuk, A. V., Wenstrup, J. J., & Hamid, M. A. (2012). Tinnitus and underlying brain mechanisms. *Current Opinion in Otolaryngology and Head and Neck Surgery*, *20*(5), 409–415. https://doi.org/10.1097/MOO.0b013e3283577b81

Gallo, K. E. B., Corrêa, C. de C., Gonçalves, C. G. de O., Correia Baran, J. B., Marques, J. M., Zeigelboim, B. S., & José, M. R. (2023). Effect of tinnitus on sleep quality and insomnia. *International Archives of Otorhinolaryngology*, *27*(02), e197–e202. https://doi.org/10.1055/s-0041-1735455

GaStat. (2017). *Population annual growth rate in Saudi Arabia is 2.52%*. General Authority for Statistics. Retrieved from https://www.stats.gov.sa/en/w/gastat-population-annual-growth-rate-in-saudi-arabia-is-2.52-

Giese, D., Li, H., Liu, W., Staxäng, K., Hodik, M., Ladak, H. M., Agrawal, S., Schrott Fischer, A., Glueckert, R., & Rask-Andersen, H. (2024). Microanatomy of the human tunnel of Corti structures and cochlear partition-tonotopic variations and transcellular signaling. *Journal of Anatomy*. https://doi.org/10.1111/joa.14045

Goderie, T., Van Wier, M. F., Lissenberg-Witte, B. I., Merkus, P., Smits, C., Leemans, C. R., & Kramer, S. E. (2022). Factors associated with the development of tinnitus and with the degree of annoyance caused by newly developed tinnitus. *Ear and Hearing*, *43*(6), 1807–1815. https://doi.org/10.1097/AUD.0000000000001250

Gos, E., Sagan, A., Skarzynski, P. H., & Skarzynski, H. (2020). Improved measurement of tinnitus severity: Study of the dimensionality and reliability of the Tinnitus Handicap Inventory. *PLoS ONE*. https://doi.org/10.1371/journal.pone.0237778

Grewal, R., Spielmann, P. M., Jones, S. E. M., & Hussain, S. S. M. (2014). Clinical efficacy of tinnitus retraining therapy and cognitive behavioural therapy in the treatment of subjective tinnitus: A systematic review. *Journal of Laryngology and Otology*, *128*(12), 1028–1033. https://doi.org/10.1017/S0022215114002849

Greenberg, D., Meerton, L., & Graham, J. (2015). Developing an assessment approach for perceptual changes to tinnitus sound characteristics for adult cochlear implant recipients. International Journal of Audiology, 55, 392–404. https://doi.org/10.3109/14992027.2016.1172391

Hackett, T. A. (2015). Anatomic organization of the auditory cortex. In *Handbook of Clinical Neurology* (Vol. 129).

Haider, H., Fackrell, K., Kennedy, V., & Hall, D. A. (2016). *Dimensions of tinnitus-related complaints reported by patients and their significant others: protocol for a systematic review*. *6*. https://doi.org/10.1136/bmjopen-2015

Hallam, R., Rachman, S., & Hinchcliffe, R. (1984). *Psychological Aspects of Tinnitus*. https://www.researchgate.net/publication/334670480

Hallam, R. S. (2009). *TQ: manual of the tinnitus questionnaire*. Polpresa Press.

Haider, H. F., Bojić, T., Ribeiro, S. F., Paço, J., Hall, D. A., & Szczepek, A. J. (2018). Pathophysiology of subjective tinnitus: Triggers and maintenance. *Frontiers in Neuroscience*, *12*(NOV). Frontiers Media S.A. https://doi.org/10.3389/fnins.2018.00866

Haile, L. M., Kamenov, K., Briant, P. S., Orji, A. U., Steinmetz, J. D., Abdoli, A., Abdollahi, M., Abu-Gharbieh, E., Afshin, A., Ahmed, H., Rashid, T. A., Akalu, Y., Alahdab, F., Alanezi, F. M., Alanzi, T. M., Al Hamad, H., Ali, L., Alipour, V., Al-Raddadi, R. M., … Chadha, S. (2021). Hearing loss prevalence and years lived with disability, 1990-2019: Findings from the Global Burden of Disease Study 2019. *The Lancet*, *397*(10278), 996–1009. https://doi.org/10.1016/S0140-6736(21)00516-X

Hall, D. A., Láinez, M. J. A., Newman, C. W., Sanchez, T., Egler, M., Tennigkeit, F., Koch, M., & Langguth, B. (2011). Treatment options for subjective tinnitus: Self reports from a sample of general practitioners and ENT physicians within Europe and the USA. *BMC Health Services Research*, *11*. https://doi.org/10.1186/1472-6963-11-302

Hall, D. A., Haider, H., Szczepek, A. J., Lau, P., Rabau, S., Jones-Diette, J., Londero, A., Edvall, N. K., Cederroth, C. R., Mielczarek, M., Fuller, T., Batuecas-Caletrio, A., Brueggemen, P., Thompson, D. M., Norena, A., Cima, R. F. F., Mehta, R. L., & Mazurek, B. (2016). Systematic review of outcome domains and instruments used in clinical trials of tinnitus treatments in adults. *Trials*, *17*(1). https://doi.org/10.1186/s13063-016-1399-9

Hall, D. A., Fackrell, K., Li, A. B., Thavayogan, R., Smith, S., Kennedy, V., Tinoco, C., Rodrigues, E. D., Campelo, P., Martins, T. D., Lourenço, V. M., Ribeiro, D., & Haider, H. F. (2018a). A narrative synthesis of research evidence for tinnitus-related complaints as reported by patients and their significant others. In *Health and Quality of Life Outcomes* (Vol. 16, Issue 1). BioMed Central Ltd. https://doi.org/10.1186/s12955-018-0888-9

Hall, D. A., Smith, H., Hibbert, A., Colley, V., Haider, H. F., Horobin, A., Londero, A., Mazurek, B., Thacker, B., & Fackrell, K. (2018b). The COMiT'ID Study: Developing core outcome domains sets for clinical trials of sound-, psychology-, and pharmacology-based interventions for chronic subjective tinnitus in adults. *Trends in Hearing*, *22*. https://doi.org/10.1177/2331216518814384

Hall, D. A., Zaragoza Domingo, S., Hamdache, L. Z., Manchaiah, V., Thammaiah, S., Evans, C., & Wong, L. L. N. (2018c). A good practice guide for translating and adapting hearing-related questionnaires for different languages and cultures. In *International Journal of Audiology* (Vol. 57, Issue 3, pp. 161–175). Taylor and Francis Ltd. https://doi.org/10.1080/14992027.2017.1393565

Hall, D. A., Xiong, B., Li, W., Wang, Y., Zhang, X., & Zhao, F. (2023). Why is tinnitus a problem? A large-scale qualitative evaluation of problems reported by tinnitus patients in mainland China. *International Journal of Audiology*. https://doi.org/10.1080/14992027.2023.2199441

Ham, J., Towle, A., & Shyng, G. (2021). Deaf and hard of hearing awareness training: A mentor-led workshop. *Clinical Teacher*, *18*(2), 180–185. https://doi.org/10.1111/tct.13304

Hamill, A. C., & Stein, C. H. (2011). Culture and empowerment in the Deaf community: An analysis of internet weblogs. *Journal of Community and Applied Social Psychology*, *21*(5), 388–406. https://doi.org/10.1002/casp.1081

Hamilton, L. S., Oganian, Y., Hall, J., & Chang, E. F. (2021). Parallel and distributed encoding of speech across human auditory cortex. *Cell*, *184*(18), 4626-4639.e13. https://doi.org/10.1016/j.cell.2021.07.019

Han, B. I., Lee, H. W., Kim, T. Y., Lim, J. S., & Shin, K. S. (2009). Tinnitus: Characteristics, causes, mechanisms, and treatments. *Journal of Clinical Neurology (Korea)*, *5*(1), 11–19. Korean Neurological Association. https://doi.org/10.3988/jcn.2009.5.1.11

Handscomb, L., Shorter, G. W., Hoare, D. J., & Hall, D. A. (2020). Evaluation of a cognitive behavioural model of tinnitus distress: a cross-sectional study using structural equation modeling. *Ear and Hearing*, *41*(4), 1028–1039. https://doi.org/10.1097/AUD.0000000000000826

He, W., Burwood, G., Fridberger, A., Nuttall, A. L., & Ren, T. (2022). An outer hair cell powered global hydromechanical mechanism for cochlear amplification. *Hearing Research*, *423*. https://doi.org/10.1016/j.heares.2021.108407

Heale, R., & Twycross, A. (2015). Validity and reliability in quantitative studies. *Evidence Based Nursing*, *18*(3), 66–67. BMJ Publishing Group. https://doi.org/10.1136/eb-2015-102129

Hearing Care Industry Association. (2017). *Social and Economic Cost of Hearing Loss in Australia*. Deloitte Access Economics. Retrieved from https://hcia.com.au/wp-content/uploads/2024/01/Social-and-Economic-Cost-of-Hearing-Health-in-Australia_June-2017.pdf

Heffernan, E., Withanachchi, C. M., & Ferguson, M. A. (2022). 'The worse my hearing got, the less sociable I got': a qualitative study of patient and professional views of the management of social isolation and hearing loss. *Age and Ageing*, *51*(2). https://doi.org/10.1093/ageing/afac019

Hennink, M. M., Kaiser, B. N., & Marconi, V. C. (2017). Code saturation versus meaning Saturation: how many interviews are enough? *Qualitative Health Research*, *27*(4), 591–608. SAGE Publications Inc. https://doi.org/10.1177/1049732316665344

Hennink, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. Social Science & Medicine, 292, 114523

Henton, A., & Tzounopoulos, T. (2021). What's the buzz? The neuroscience and the treatment of tinnitus. *Physiological Reviews*, *101*(4), 1609–1632. https://doi.org/10.1152/physrev.00029.2020

Henry, J. A., Griest, S., Zaugg, T. L., Thielman, E., Kaelin, C., Galvez, G., & Carlson, K. F. (2015). Tinnitus and hearing survey: A screening tool to differentiate bothersome tinnitus from hearing difficulties. *American Journal of Audiology*, *24*(1), 66–77. https://doi.org/10.1044/2014_AJA-14-0042

Henry, J. A., Goodworth, M. C., Lima, E., Zaugg, T., & Thielman, E. J. (2022). Cognitive Behavioral therapy for tinnitus: addressing the controversy of its clinical delivery by audiologists. *Ear and Hearing*, *43*(2), 283–289. https://doi.org/10.1097/AUD.0000000000001150

He, W., Burwood, G., Fridberger, A., Nuttall, A. L., & Ren, T. (2022). An outer hair cell-powered global hydromechanical mechanism for cochlear amplification. *Hearing Research*, *423*. https://doi.org/10.1016/j.heares.2021.108407

Hickman, T. T., Smalt, C., Bobrow, J., Quatieri, T., & Liberman, M. C. (2018). Blast-induced cochlear synaptopathy in chinchillas. *Scientific Reports*, *8*(1). https://doi.org/10.1038/s41598-018-28924-7

Hiller, W., & Goebel, G. (1992). A psychometric study of complaints in Chronic tinnitus. *Journal of Psychosomatic Research* (Vol. 36, Issue 4).

Hiller, W., & Goebel, G. (2004). Rapid assessment of tinnitus-related psychological distress using the Mini-TQ. *International Journal of Audiology*, *43*(10), 600–604. https://doi.org/10.1080/14992020400050077

Hoare, D. J., Smith, H., Kennedy, V., & Fackrell, K. (2024). Tinnitus in Children. *JARO – Journal of the Association for Research in Otolaryngology*, *25*(3), 239–247. Springer. https://doi.org/10.1007/s10162-024-00944-3

Hu, J., Cui, J., Xu, J. J., Yin, X., Wu, Y., & Qi, J. (2021). The neural mechanisms of tinnitus: a perspective from functional magnetic resonance imaging. *Frontiers in Neuroscience*, *15*. Frontiers Media S.A. https://doi.org/10.3389/fnins.2021.621145

Huddle, M. G., Goman, A. M., Kernizan, F. C., Foley, D. M., Price, C., Frick, K. D., & Lin, F. R. (2017). The economic impact of adult hearing loss: A systematic review. *JAMA Otolaryngology - Head and Neck Surgery*, *143*(10), 1040–1048. American Medical Association. https://doi.org/10.1001/jamaoto.2017.1243

Humble, S. (2020). Quantitative analysis of questionnaires: Techniques to explore structures and relationships. *Routledge.*

Ito, J. (1994a). Tinnitus suppression by electrical stimulation of the cochlear wall and by cochlear implantation. Laryngoscope, 104, 752–754. https://doi.org/10.1288/00005537-199406000-00017

Ito, J. (1994b). Suppression of tinnitus by cochlear implantation. American Journal of Otolaryngology, 15, 145–148. https://doi.org/10.1016/0196-0709(94)90064-7

Jarach, C. M., Lugo, A., Scala, M., Van Den Brandt, P. A., Cederroth, C. R., Odone, A., Garavello, W., Schlee, W., Langguth, B., & Gallus, S. (2022). Global prevalence and incidence of tinnitus: a systematic review and meta-analysis. *JAMA Neurology*, *79*(9), 888–900. https://doi.org/10.1001/jamaneurol.2022.2189

Jastreboff, P. J. (1990). Phantom auditory perception (tinnitus): mechanisms of generation and perception. *Neuroscience Research*, *8*.

Jastreboff, P. J., & Hazell, J. W. P. (1993). A neurophysiological approach to tinnitus: clinical implications. *British Journal of Audiology*, *27*.

Jastreboff, P. J., & Jastreboff, M. M. (2003). Tinnitus retraining therapy for patients with tinnitus and decreased sound tolerance. *Otolaryngologic Clinics of North America*, *36*(2), 321–336. https://doi.org/10.1016/S0030-6665(02)00172-X

Jørgensen, A. Y., Aarhus, L., Engdahl, B., Bratsberg, B., Skirbekk, V. F., & Mehlum, I. S. (2022). Hearing loss, sick leave, and disability pension: findings from the HUNT follow-up study. *BMC Public Health*, *22*(1). https://doi.org/10.1186/s12889-022-13760-2

Kaltenbach, J. A. (2011). Tinnitus: models and mechanisms. *Hearing Research*, *276*(1–2), 52–60. https://doi.org/10.1016/j.heares.2010.12.003

Ketterer, M. C., Häussler, S. M., Hildenbrand, T., Speck, I., Peus, D., Rosner, B., et al. (2020). Binaural hearing rehabilitation improves speech perception, quality of life, tinnitus distress, and psychological comorbidities. Otology & Neurotology, 41, e563–e574. https://doi.org/10.1097/MAO.0000000000002590

Kim, D. K., Bae, S. C., Park, K. H., Jun, B. C., Lee, D. H., Yeo, S. W., et al. (2013). Tinnitus in patients with profound hearing loss and the effect of cochlear implantation. European Archives of Oto-Rhino-Laryngology, 270, 1803–1808. https://doi.org/10.1007/s00405-012-2193-2

Kim, H.-J., Lee, H.-J., An, S.-Y., Sim, S., Park, B., Kim, S. W., Lee, J. S., Hong, S. K., & Choi, H. G. (2015). Analysis of the prevalence and associated risk factors of Tinnitus in adults. *PLoS ONE*, *10*(5), e0127578. https://doi.org/10.1371/journal.pone.0127578

Kim, D. K., Moon, I. S., Lim, H. J., Yoo, S. Y., Heo, K. W., Bae, S., et al. (2016). Prospective, multicenter study on tinnitus changes after cochlear implantation. Audiology and Neurotology, 21, 165–171. https://doi.org/10.1159/000445164

Kim, S. H., Kim, D., Lee, J.-M., Lee, S. K., Kang, H. J., Yeo, S. G., Kim, S. H., Kim, D., Lee, J.-M., Lee, S. K., Kang, H. J., Yeo, S. G., Stadio, A. D., & Ralli, M. (2021). Healthcare review of pharmacotherapy for tinnitus. *Healthcare*. https://doi.org/10.3390/healthcare9080951

Kiernan, J. A. (2012). Anatomy of the temporal lobe. *Epilepsy Research and Treatment*, *2012*, 1–12. https://doi.org/10.1155/2012/176157

Knopke, S., Gräbel, S., Förster-Ruhrmann, U., Mazurek, B., Szczepek, A. J., & Olze, H. (2016). Impact of cochlear implantation on quality of life and mental comorbidity in patients aged 80 years. *Laryngoscope,* 126, 2811–2816. https://doi.org/10.1002/lary.25993

Knopke, S., Szczepek, A. J., Häussler, S. M., & Gräbel, S. (2017). Cochlear implantation of bilaterally deafened patients with tinnitus induces sustained decrease of tinnitus-related distress. *Frontiers in Neurology*, 8, 158. https://doi.org/10.3389/fneur.2017.00158

Khan, R. A., Sutton, B. P., Tai, Y., Schmidt, S. A., Shahsavarani, S., & Husain, F. T. (2021). A large-scale diffusion imaging study of tinnitus and hearing loss. *Scientific Reports*, *11*(1). https://doi.org/10.1038/s41598-021-02908-6

Kleinstäuber, M., Jasper, K., Schweda, I., Hiller, W., Andersson, G., & Weise, C. (2013). The Role of fear-avoidance cognitions and behaviors in patients with chronic tinnitus. *Cognitive Behaviour Therapy*, *42*(2), 84–99. https://doi.org/10.1080/16506073.2012.717301

Klomjai, W., Katz, R., & Lackmy-Vallée, A. (2015). Basic principles of transcranial magnetic stimulation (TMS) and repetitive TMS (rTMS). *Annals of Physical and Rehabilitation Medicine*, *58*(4), 208–213. https://doi.org/10.1016/j.rehab.2015.05.005

Knipper, M., van Dijk, P., Schulze, H., Mazurek, B., Krauss, P., Scheper, V., Warnecke, A., Schlee, W., Schwabe, K., Singer, W., Braun, C., Delano, P. H., Fallgatter, A. J., Ehlis, A. C., Searchfield, G. D., Munk, M. H. J., Baguley, D. M., & Rüttiger, L. (2020). The neural bases of tinnitus: lessons from deafness and cochlear implants. *Journal of Neuroscience*, *40*(38), 7190–7202. https://doi.org/10.1523/JNEUROSCI.1314-19.2020

Kramer, S. E., Kapteyn, T. S., & Houtgast, T. (2006). Occupational performance: comparing

Normally hearing and hearing-impaired employees using the amsterdam checklist for hearing and work. *International Journal of Audiology*, *45*(9), 503–512. https://doi.org/10.1080/14992020600754583

Kujawa, S. G., & Liberman, M. C. (2015). Synaptopathy in the noise-exposed and aging cochlea: Primary neural degeneration in acquired sensorineural hearing loss. *Hearing Research*, *330*, 191–199. https://doi.org/10.1016/j.heares.2015.02.009

Kuk, F. K., Tyler, R. S., Russell, D., & Jordan, H. (1990). Amplification and aural Rehabilitation the psychometric properties of a tinnitus handicap questionnaire

Labree, B., Hoare, D. J., Gascoyne, L. E., Scutt, P., Del Giovane, C., & Sereda, M. (2022). Determining the effects of transcranial direct current stimulation on tinnitus, depression, and anxiety: a systematic review. *Brain Sciences*, *12*(4), 484. https://doi.org/10.3390/brainsci12040484

Lan, L., Li, J., Chen, Y., Chen, W., Li, W., Zhao, F., Chen, G., Liu, J., Chen, Y., Li, Y., Wang, C. D., Zheng, Y., & Cai, Y. (2021). Alterations of brain activity and functional connectivity in transition from acute to chronic tinnitus. *Human Brain Mapping*, *42*(2), 485–494. https://doi.org/10.1002/hbm.25238

Landry, E. C., Sandoval, X. C. R., Simeone, C. N., Tidball, G., Lea, J., & Westerberg, B. D. (2020). Systematic review and network meta-analysis of cognitive and/or behavioral therapies (cbt) for tinnitus. *Otology and Neurotology*, *41*(2), 153–166. https://doi.org/10.1097/MAO.0000000000002472

Langguth, B., de Ridder, D., Schlee, W., & Kleinjung, T. (2024). Tinnitus: clinical insights In its pathophysiology—a perspective. *JARO - Journal of the Association for Research in Otolaryngology*, *25*(3), 249-258. https://doi.org/10.1007/s10162-024-00939-0

Langguth, B., Elgoyhen, A. B., & Cederroth, C. R. (2018). Therapeutic approaches to the Treatment of tinnitus. *Annual Review of Pharmacology and Toxicology*, *59*, 277-297. https://doi.org/10.1146/annurev-pharmtox-010617-052844

Langguth, B., Kreuzer, P. M., Kleinjung, T., & De Ridder, D. (2013). Tinnitus: causes and

Clinical management. *The Lancet Neurology*, *12*(9), 920-930. https://doi.org/10.1016/S1474-4422(13)70160-1

Lanting, C. P., de Kleine, E., & van Dijk, P. (2009). Neural activity underlying tinnitus generation: Results from PET and fMRI. *Hearing Research*, *255*(1–2), 1–13. https://doi.org/10.1016/j.heares.2009.06.009

Lasch, K. E., Marquis, P., Vigneux, M., Abetz, L., Arnould, B., Bayliss, M., Crawford, B., & Rosa, K. (2010). PRO development: Rigorous qualitative research as the crucial foundation. *Quality of Life Research*, *19*(8), 1087–1096. https://doi.org/10.1007/s11136-010-9677-6

Larsen, P. D. (Ed.). (2021). Lubkin's chronic illness: Impact and intervention (11th ed.). *Jones & Bartlett Learning.* http://samples.jblearning.com/9781284230642/9781284230642_CH01_SECURE.pdf

Lethem, J., Slade, P. D., G Troupe, J. D., & Bentley, G. (1983). Outline of a fear avoidance model of exaggerated pain perception-I. *Behaviour Research and Therapy*, *21*(4), 401-408.

Liang, Z., Yang, H., Cheng, G., Huang, L., Zhang, T., & Jia, H. (2020). Repetitive transcranial magnetic stimulation on chronic tinnitus: a systematic review and meta-analysis. *BMC Psychiatry*, *20*(1), 582. https://doi.org/10.1186/s12888-020-02947-9

Liberman, M. C., & Kujawa, S. G. (2017). Cochlear synaptopathy in acquired sensorineural hearing loss: Manifestations and mechanisms. *Hearing Research*, *349*, 138–147. https://doi.org/10.1016/j.heares.2017.01.003

Lieu, J. E. C., Kenna, M., Anne, S., & Davidson, L. (2020). Hearing loss in children: a Review. *JAMA*, *324*(21), 2195–2205. https://doi.org/10.1001/jama.2020.17647

Lin, D., & Selleck, A. M. (2023). Tinnitus cases after COVID-19 vaccine administration, one institution's observations. *American Journal of Otolaryngology*, *44*(4), 103863. https://doi.org/10.1016/j.amjoto.2023.103863

Lindberg, P. (1988). Effects of self-control training on tinnitus in a deaf patient: A case study. *Cognitive Behaviour Therapy*, 17(2), 79-82.

Liu, Y., Wang, H., Han, D. X., Li, M. H., & Wang, Y. (2016). Suppression of tinnitus in Chinese patients receiving regular cochlear implant programming. *Annals of Otology, Rhinology & Laryngology,* 125, 303–310. https://doi.org/10.1177/0003489415611907

Liu, H., Chen, L., Giffen, K. P., Stringham, S. T., Li, Y., Judge, P. D., Beisel, K. W., & He, D. Z. Z. (2018). Cell-specific transcriptome analysis shows that adult pillar and deiters' cells express genes encoding machinery for specializations of cochlear hair cells. *Frontiers in Molecular Neuroscience*, *11*, 356. https://doi.org/10.3389/fnmol.2018.00356

Liyanage, S., Saqib, K., Khan, A. F., Thobani, T. R., Tang, W.-C., Chiarot, C. B., AlShurman, B. A., & Butt, Z. A. (2025). Prevalence of anxiety in university students during the covid-19 pandemic: a systematic review. *International Journal of Environmental Research and Public Health,* 19(1), 62. https://doi.org/10.3390/ijerph19010062

Llano, D. A., Turner, J., & Caspary, D. M. (2012). Diminished cortical inhibition in an aging mouse model of chronic tinnitus. *Journal of Neuroscience*, *32*(46), 16141–16148. https://doi.org/10.1523/JNEUROSCI.2499-12.2012

Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy*, *33*(3), 335-343.

Lund, T. (2012). Combining Qualitative and Quantitative Approaches: Some Arguments for Mixed Methods Research. *Scandinavian Journal of Educational Research*, *56*(2), 155–165. https://doi.org/10.1080/00313831.2011.568674

Main, C. J. (1983). The modified somatic perception questionnaire (MSPQ). *Journal of Psychosomatic Research, 27*(6), 503–514. https://doi.org/10.1016/0022-3999(83)90040-5

Manchaiah, V. K. C., & Stephens, D. (2013). Life consequences and positive experiences reported by communication partners of people with hearing impairment: A pilot study. *Speech, Language and Hearing*, *16*(1), 2–8. https://doi.org/10.1179/2050571X12Z.0000000004

Matsuzaki, S., Oishi, N., & Ogawa, K. (2018). Severe tinnitus in a patient with acquired deafness for over 50years: A case report. *BioPsychoSocial Medicine*, *12*(1). https://doi.org/10.1186/s13030-018-0136-x

MacroTrends. (2025). *Saudi Arabia Population 1950-2025*. Retrieved from https://www.macrotrends.net/global-metrics/countries/sau/saudi-arabia/population

Mann, Z. F., & Kelley, M. W. (2011). Development of tonotopy in the auditory periphery. *Hearing Research*, *276*(1–2), 2–15. https://doi.org/10.1016/j.heares.2011.01.011

Manno, F.A.M., et al. (2021). "Hearing loss impacts gray and white matter across the lifespan." *NeuroImage: Clinical*, 30, 102616. [PMC8236095] https://scholars.cityu.edu.hk/files/78455902/70882803.pdf.pdf

Mao, B., Balasubramanian, T., & Kelley, M. W. (2020). Cochlear development, cellular patterning and tonotopy. *Current Opinion in Physiology*, *18*, 116–122. https://doi.org/10.1016/j.cophys.2020.09.010

Marks, E., Smith, P., & McKenna, L. (2019). Living with tinnitus and the health care journey: An interpretative phenomenological analysis. *British Journal of Health Psychology*, *24*(2), 250–264. https://doi.org/10.1111/bjhp.12351

Mays, N., & Pope, C. (2000). Qualitative research in health care: assessing quality in Qualitative research.

McCombe, A., Baguley, D., Coles, R., McKenna, L., McKinney, C., & Windle-Taylor, P. (2001). Guidelines for the grading of tinnitus severity: The results of a working group commissioned by the British Association of Otolaryngologists, Head and Neck Surgeons, 1999. *Clinical Otolaryngology and Allied Sciences*, *26*(5), 388–393. https://doi.org/10.1046/j.1365-2273.2001.00490.x

McCormack, A., Edmondson-Jones, M., Somerset, S., & Hall, D. (2016). A systematic review of the reporting of tinnitus prevalence and severity. *Hearing Research*, *337*, 70–79. https://doi.org/10.1016/j.heares.2016.05.009

McKenna, L. (2004). Models of tinnitus suffering and treatment compared and contrasted. *Audiological Medicine*, *2*(1), 41–53. https://doi.org/10.1080/16513860410028735

McKenna, L., Handscomb, L., Hoare, D. J., & Hall, D. A. (2014). A scientific cognitive behavioral model of tinnitus: Novel conceptualizations of tinnitus distress. *Frontiers in Neurology*, *5*, 196. https://doi.org/10.3389/fneur.2014.00196

Meikle, M., Henry, J., Griest, S., Stewart, B., Abrams, H., McArdle, R., Myers, P., Newman, C., Sandridge, S., Turk, D., Folmer, R., Fredrick, E., House, JJ.,Jacobson, G., Kinney, S. , Martin, WW.,Nagler, S. , Reich, G. , Searchfield, G., … Vernon, J. (2012). *The Tinnitus Functional Index_ Development of a New Clinical Measure for Chronic, Intrusive Tinnitus-3*.

Michels, T. C., Duffy, M. T., & Rogers, D. J. (2019). Hearing loss in adults: differential Diagnosis and treatment. *American Family Physician*, *100*(2), 98-108.

Milinski, L., Nodal, F. R., Vyazovskiy, V. V., & Bajo, V. M. (2022). Tinnitus: At a crossroad between phantom perception and sleep. *Brain Communications*, *4*(3). https://doi.org/10.1093/braincomms/fcac089

Miller, K., & Tseng, J. (2024). Optimising healthcare for Deaf and hard of hearing patients. *Prescriber*, *35*(3), 19–24. https://doi.org/10.1002/psb.2127

Miyamoto, R. T., Wynne, M. K., & McKnight, C. (1997). Electrical suppression of tinnitus

via cochlear implants. *International Tinnitus Journal*, 3, 35–38.

Moerel, M., De Martino, F., & Formisano, E. (2014). An anatomical and functional topography of human auditory cortical areas. *Frontiers in Neuroscience*, *8*, 225. https://doi.org/10.3389/fnins.2014.00225

Mohan, A., Leong, S. L., De Ridder, D., & Vanneste, S. (2022). Symptom dimensions to address heterogeneity in tinnitus. *Neuroscience and Biobehavioral Reviews*, *134*, 104542. https://doi.org/10.1016/j.neubiorev.2022.104542

Mohd Arifin, S. R., Cheyne, H., Maxwell, M., & Pien, L. S. (2019). Framework analysis: A worked example from midwifery research. *Enfermeria Clinica*, *29*, 739–746. https://doi.org/10.1016/j.enfcli.2019.04.112

Mokkink, L., Elsman, E., & Terwee, C. (2024). COSMIN guideline for systematic reviews of patient-reported outcome measures version 2.0. *Quality of Life Research*. https://doi.org/10.1007/s11136-024-03761-6

Mokkink, L. , Prinsen, C. , Patrick, D. , Alonso, J. , Bouter, L. , CW de Vet., H. &, & Terwee, C. (2019). COSMIN Study Design checklist for Patient-reported outcome measurement instruments. www.cosmin.nl

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health*, *17*(1), 1–16. https://doi.org/10.1080/08870440290001494

Moussa, M. T., Lovibond, P., Laube, R., & Megahead, H. A. (2017). Psychometric properties Of an arabic version of the Depression Anxiety Stress Scales (DASS). *Research on Social Work Practice*, *27*(3), 375–386. https://doi.org/10.1177/1049731516662916

Munn, Z., Peters, M. D. J., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, *18*(1), 143.

https://doi.org/10.1186/s12874-018-0611-x

Nagy, W. E. (2005). Why vocabulary instruction needs to be long-term and comprehensive. In E. H. Hiebert & M. L. Kamil (Eds.), *Teaching and learning vocabulary: Bringing research to practice* (pp. 27–44). Lawrence Erlbaum Associates.

Natarajan, N., Batts, S., & Stankovic, K. M. (2023). Noise-Induced Hearing Loss. *Journal of Clinical Medicine*, *12*(6), 2347. https://doi.org/10.3390/jcm12062347

National Institute for Health and Care Excellence. (2018). Hearing loss in adults: Assessment and management (NICE Guideline NG98). https:// www.nice.org.uk/guidance/ng98

National Institute for Health and Care Excellence. (2019). Cochlear implants for children and adults with severe to profound deafness (NICE Guidelines TA566). www.nice.org.uk/guidance/ta566

National Institute for Health and Care Excellence. (2020). Tinnitus: assessment and management (NICE Guideline NG155). https://www.nice.org.uk/guidance/ng155

National Institute for Health and Care Excellence. (2019). Cochlear implants for severe-to profound deafness (TA566). Available: www.nice.org.uk/guidance/ta566

Neuman, A. C., Waltzman, S. B., Shapiro, W. H., Neukam, J. D., Zeman, A. M., & Svirsky, M. A. (2017). Self-reported usage, functional benefit, and audiologic characteristics of cochlear implant patients who use a contralateral hearing aid. *Trends in Hearing*, *21*, 2331216517699530. https://doi.org/10.1177/2331216517699530

Newman, C. W., Jacobson, G. P., Spitzer, J. B., Surgery, N., Ford Hospital, H., & Newman, M. (1996). Development of the Tinnitus Handicap Inventory from the Division of Audiology, Department of Otolaryngology\p=m-\Head and. *Archives of Otolaryngology—Head & Neck Surgery*, *122*(2), 143-148

Nondahl, D. M., Cruickshanks, K. J., Wiley, T. L., Klein, B. E. K., Klein, R., Chappell, R., & Tweed, T. S. (2010). The ten-year incidence of tinnitus among older adults. *International Journal of Audiology*, *49*(8), 580–585. https://doi.org/10.3109/14992021003753508

Nourski, K. V. (2017). Auditory processing in the human cortex: An intracranial electrophysiology perspective. *Laryngoscope Investigative Otolaryngology*, *2*(4), 147–156. https://doi.org/10.1002/lio2.73

Olze, H., Szczepek, A. J., Haupt, H., Förster, U., Zirke, N., Gräbel, S., et al. (2011). Cochlear implantation has a positive influence on quality of life, tinnitus, and psychological comorbidity. *Laryngoscope,* 121, 2220–2227. https://doi.org/10.1002/lary.22145

Olze, H., Gräbel, S., Förster, U., Zirke, N., Huhnd, L. E., Haupt, H., et al. (2012a). Elderly patients benefit from cochlear implantation regarding auditory rehabilitation, quality of life, tinnitus, and stress. *Laryngoscope*, 122, 196-203. https://doi.org/10.1002/lary.22356

Olze, H., Gräbel, S., Haupt, H., & Förster, U. (2012b). Extra benefit of a second cochlear implant with respect to health-related quality of life and tinnitus. *Otology & Neurotology*, 33, 1169–1175. https://doi.org/10.1097/MAO.0b013e31825e799

Olze, H., Szczepek, A. J., Haupt, H., Zirke, N., Graebel, S., & Mazurek, B. (2012c). The impact of cochlear implantation on tinnitus, stress and quality of life in postlingually deafened patients. *Audiology and Neurotology*, 17, 2-11. https://doi.org/10.1159/000323847

Palau, E. M., Gil, J. L. M., Vidal, C. M., González, J. C. F., & Cabrera, O. A. (2010). Acúfeno e implante coclear. *Acta Otorrinolaringológica Española*, 61, 405–411. https://doi.org/10.1016/j.otorri.2010.07.001

Palumbo, D. B., Joos, K., De Ridder, D., & Vanneste, S. (2015). The Management and Outcomes of Pharmacological Treatments for Tinnitus. *Current Neuropharmacology*, *13*.

Pan, T., Tyler, R., Ji, H., Coelho, C., & Gehringer, A. (2009). Changes in the tinnitus handicap questionnaire after cochlear implantation. *American Journal of Audiology*, 18, 144–151. https://doi.org/10.1044/1059-0889(2009/07-0042)

Parkinson, S., Eatough, V., Holmes, J., Stapley, E., & Midgley, N. (2016). Framework analysis: a worked example of a study exploring young people's experiences of depression. *Qualitative Research in Psychology*, *13*(2), 109–129.

Patrick, D. L., Burke, L. B., Gwaltney, C. J., Leidy, N. K., Martin, M. L., Molsen, E., & Ring, L. (2011). Content validity - Establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO good research practices task force report: Part 1 - Eliciting concepts for a new PRO instrument. *Value in Health*, *14*(8), 967–977. https://doi.org/10.1016/j.jval.2011.06.014

Patton, M. Q. (1999). *Enhancing the quality and credibility of qualitative analysis*. Health Services Research, *34*(5 Pt 2), 1189–1208.

Pelaseyed, T., & Bretscher, A. (2018). Regulation of actin-based apical structures on epithelial cells. *Journal of Cell Science*, *131*(20). Company of Biologists Ltd. https://doi.org/10.1242/jcs.221853

Peters, M. D. J., Godfrey, C. M., Khalil, H., McInerney, P., Parker, D., & Soares, C. B. (2015). Guidance for conducting systematic scoping reviews. *International Journal of Evidence-Based Healthcare*, *13*(3), 141–146. https://doi.org/10.1097/XEB.0000000000000050

Peter, N., Kleinjung, T., Jeker, R., Meyer, M., Klaghofer, R., & Weidt, S. (2017). Tinnitus Functional index: validation of the German version for Switzerland. *Health and Quality of Life Outcomes*, *15*(1). https://doi.org/10.1186/s12955-017-0669-x

Peters, M. D. J., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C. M., & Khalil, H. (2020). Updated methodological guidance for the conduct of scoping reviews. *JBI Evidence Synthesis*, *18*(10), 2119–2126. https://doi.org/10.11124/JBIES-20-00167

Phillips, J. S., McFerran, D. J., Hall, D. A., & Hoare, D. J. (2018). The natural history of subjective tinnitus in adults: A systematic review and meta-analysis of no-intervention periods in controlled trials. In *Laryngoscope* (Vol. 128, Issue 1, pp. 217–227). John Wiley and Sons Inc. https://doi.org/10.1002/lary.26607

Pickles, J. O. (2015). *Auditory pathways: anatomy and physiology*.

Pierzycki, R. H., Edmandson-Jones, M., Dawes, P., Munro, K. J., & Moore, D. R. (2016). Tinnitus and sleep difficulties after cochlear implantation. *Ear and Hearing*, 37, e402–e408. https://doi.org/10.1097/AUD.0000000000000341

Pierzycki, R. H. (2021). Insomnia, anxiety and depression in adult cochlear implant users with tinnitus. *Ear and Hearing*, 42, 235–243. https://doi.org/10.1097/AUD.0000000000000900

Pisani, D., Gioacchini, F. M., Viola, P., Scarpa, A., Astorina, A., Re, M., Marcianò, G., Manti, F., Anzivino, R., & Chiarella, G. (2022). Audiovestibular Disorders after COVID-19 Vaccine: Is There an Association? In *Audiology Research* (Vol. 12, Issue 3, pp. 212–223). Page Press Publications. https://doi.org/10.3390/audiolres12030024

Plano Clark, V. L., & Ivankova, N. V. (2018). Mixed Methods Research: A Guide to the Field. *SAGE Publications, Inc.* https://doi.org/10.4135/9781483398341

Pope, C., Ziebland, S., & Mays, N. (2009). Qualitative research in health care: Analysing qualitative data. www.bmj.com

Pryce, H., Dauman, N., & Burns-O'Connell, G. (2023). What is the burden of tinnitus?

Frontiers in Psychology, *13*. https://doi.org/10.3389/fpsyg.2022.981776

Quaranta, N., Fernandez-Vega, S., D'elia, C., & Filipo, R. (2008). The effect of unilateral multichannel cochlear implant on bilaterally perceived tinnitus. Acta Oto-Laryngologica, 128, 159–163. https://doi.org/10.1080/00016480701387173

Rademaker, M. M., Essers, B. A. B., Stokroos, R. J., Smit, A. L., & Stegeman, I. (2021). What tinnitus therapy outcome measures are important for patients?– a discrete choice experiment. *Frontiers in Neurology*, *12*. https://doi.org/10.3389/fneur.2021.668880

Ramakers, G. G., van Zanten, G. A., Thomeer, H. G., Stokroos, R. J., & Heymans, M. W. (2018). Development and internal validation of a multivariable prediction model for tinnitus recovery following unilateral cochlear implantation: A cross-sectional retrospective study. *BMJ Open*, 8, e021068. https://doi.org/10.1136/bmjopen-2017-021068

Rameshbhai Patel, H., & Joseph, J. M. (2016). Questionnaire Designing Process: A Review. *Journal of Clinical Trials*, *06*(02). https://doi.org/10.4172/2167-0870.1000255

Ratnanather, J. T. (2020). Structural neuroimaging of the altered brain stemming from pediatric and adolescent hearing loss—Scientific and clinical challenges. *Wiley Interdisciplinary Reviews: Systems Biology and Medicine, 12*(2). https://doi.org/10.1002/wsbm.1469

Rattray, J., & Jones, M. C. (2007). Essential elements of questionnaire design and development. In *Journal of Clinical Nursing* (Vol. 16, Issue 2, pp. 234–243).https://doi.org/10.1111/j.1365-2702.2006.01573.x

Ritchie, J., & Lewis, J. (2003). *Qualitative research practice: A guide for social science students and researchers*. Sage Publications.

Rødvik, A. K., Myhrum, M., Larsson, E. L., & Falkenberg, E. S. (2022). Sustained reduction of tinnitus several years after sequential cochlear implantation. *International Journal of Audiology*, 61, 322–328. https://doi.org/10.1080/14992027.2021.1939448

Roberts, L. E., Eggermont, J. J., Caspary, D. M., Shore, S. E., Melcher, J. R., & Kaltenbach, J. A. (2010). Ringing ears: The neuroscience of tinnitus. *Journal of Neuroscience, 30*(45), 14972–14979. https://doi.org/10.1523/JNEUROSCI.4028-10.2010

Roze, K. C. M., Tijsseling, C., Rudd, B., & Tiemens, B. G. (2020). Measuring recovery in deaf, hard-of-hearing, and tinnitus patients in a mental health care setting: Validation of the I.ROC. *Journal of Deaf Studies and Deaf Education*, *25*(2), 178–187. https://doi.org/10.1093/deafed/enz043

Ruckenstein, M. J., Hedgepeth, C., Rafter, K. O., & Montes, M. L. (2001). Tinnitus suppression in patients with cochlear implants. *Otology & Neurotology*, 22, 200–204. https://doi.org/10.1097/00129492-200103000-00014

Salviati, M., Macrì, F., Terlizzi, S., Melcore, C., Provenzano, A., Capparelli, E., Altissimi, G., & Cianfrone, G. (2013). The Tinnitus Handicap Inventory (THI) as a Screening Test for Psychiatric Comorbidity in Patients with Tinnitus. www.psychosomaticsjournal.org

Santana, S., Brach, C., Harris, L., Ochiai, E., Blakey, C., Bevington, F., Kleinman, D., & Pronk, N. (2021). Updating health literacy for healthy people 2030: defining its importance for a new decade in public health. *Journal of Public Health Management and Practice, 27*(12), S258–S264. https://doi.org/10.1097/PHH.0000000000001324

Sarac, E. T., Batuk, M. O., & Batuk, I. T. (2020). Effects of cochlear implantation on tinnitus and depression. *ORL*, 82, 209–215. https://doi.org/10.1159/000508137

Schoisswohl, S., Agrawal, K., Simoes, J., Neff, P., Schlee, W., Langguth, B., & Schiller, A. (2021). UNification of treatments and Interventions for TInnitus patients (UNITI): A study protocol for a multi-center randomized clinical trial. *Trials, 22*(1), 875. https://doi.org/10.1186/s13063-021-05835-z

Sellon, J. B., Ghaffari, R., & Freeman, D. M. (2019). The tectorial membrane: Mechanical properties and functions. *Cold Spring Harbor Perspectives in Medicine, 9*(10). https://doi.org/10.1101/cshperspect.a033514

Searchfield, G. D. (2014). Tinnitus what and where: An ecological framework. *Frontiers in Neurology*, *5*(DEC). https://doi.org/10.3389/fneur.2014.00271

Sereda, M., Xia, J., El Refaie, A., Hall, D. A., & Hoare, D. J. (2018). Sound therapy (using amplification devices and/or sound generators) for tinnitus. *Cochrane Database of Systematic Reviews, 2018*(12). https://doi.org/10.1002/14651858.CD013094.pub2

Shan, A., Ting, J. S., Price, C., Goman, A. M., Willink, A., Reed, N. S., & Nieman, C. L. (2020). Hearing loss and employment: A systematic review of the association between hearing loss and employment among adults. *Journal of Laryngology and Otology, 134*(5), 387–397. https://doi.org/10.1017/S0022215120001012

Shargorodsky, J., Curhan, G. C., & Farwell, W. R. (2010). Prevalence and characteristics of tinnitus among US adults. *American Journal of Medicine, 123*(8), 711–718. https://doi.org/10.1016/j.amjmed.2010.02.015

Shave, S., Botti, C., & Kwong, K. (2022). Congenital Sensorineural Hearing Loss. *Pediatric Clinics of North America, 69*(2), 221–234. https://doi.org/10.1016/j.pcl.2021.12.006

Sheikh, A., Shabbir, K., & Imtiaz, A. (2022). Structure and Physiology of Human Ear Involved in Hearing. Retrieved from www.intechopen.com

Sheikh, A., Shabbir, K., & Imtiaz, A. (2022). *Structure and Physiology of Human Ear Involved in Hearing*. www.intechopen.com

Shilling-Scrivo, K., Mittelstadt, J., & Kanold, P. O. (2021). Altered response dynamics and

increased population correlation to tonal stimuli embedded in noise in aging auditory cortex. *Journal of Neuroscience, 34*(3), 9650–9668. https://doi.org/10.1523/JNEUROSCI.0839-21.2021

Shore, S. E., Roberts, L. E., & Langguth, B. (2016). Maladaptive plasticity in tinnitus triggers, mechanisms and treatment. *Nature Reviews Neurology, 12*(3), 150–160. https://doi.org/10.1038/nrneurol.2016.12

Shore, S. E., & Wu, C. (2019). Mechanisms of Noise-Induced Tinnitus: Insights from Cellular Studies. *Neuron, 103*(1), 8–20. https://doi.org/10.1016/j.neuron.2019.05.008

Simons, I. A., Goderie, T., Lissenberg-Witte, B. I., Versfeld, N. J., Kramer, S. E., & Van Wier, M. F. (2023). The Effects of Tinnitus and Tinnitus Annoyance on Need for Recovery After Work: Results of the Netherlands Longitudinal Study on Hearing. In *Ear & Hearing* (Vol. 44).

Sindhusake, D., Mitchell, P., Newall, P., Golding, M., Rochtchina, E., & Rubin, G.(2003). Prevalence and characteristics of tinnitus in older adults: The Blue Mountains Hearing Study. *International Journal of Audiology, 42*(5), 289–294. https://doi.org/10.3109/14992020309078348

Skarzynski, P. H., Swierniak, W., Rajchel, J., Dziendziel, B., & Raj-Koziak, D. (2017). Tinnitus severity in patients with cochlear implants. *Journal of Hearing Science*, 3, 29–36. https://doi.org/10.17430/904529

Smith, H., Horobin, A., Fackrell, K., Colley, V., Thacker, B., & Hall, D. A. (2018). Defining and evaluating novel procedures for involving patients in core outcome set research: Creating a meaningful long list of candidate outcome domains. *Research Involvement and Engagement*, *4*(1). https://doi.org/10.1186/s40900-018-0091-5

Smith, H., Fackrell, K., Kennedy, V., Barry, J., Partridge, L., & Hoare, D. J. (2019). A scoping review to catalogue tinnitus problems in children. In *International Journal of Pediatric Otorhinolaryngology* (Vol. 122, pp. 141–151). Elsevier Ireland Ltd. https://doi.org/10.1016/j.ijporl.2019.04.006

Song, Y., Son, Y. J., & Oh, D. (2015). Methodological issues in questionnaire design. *Journal of Korean Academy of Nursing*, *45*(3), 323–328. https://doi.org/10.4040/jkan.2015.45.3.323

Souliere, C. R., Kileny, P. R., & Zwolan, T. A. (1992). Tinnitus suppression following cochlear implantation: A multifactorial investigation. *Archives of Otolaryngology–Head & Neck Surgery*, 118(12), 1291-1297. https://doi.org/10.1001/archotol.1992.01880120017004

Spankovich, C., Gonzalez, V. B., Su, D., & Bishop, C. E. (2018). Self-reported hearing difficulty, tinnitus, and normal audiometric thresholds, the National Health and Nutrition Examination Survey 1999–2002. *Hearing Research, 358*, 30–36. https://doi.org/10.1016/j.heares.2017.12.001

Streiner, D. L., & Kottner, J. (2014). Recommendations for reporting the results of studies of instrument and scale development and testing. *Journal of Advanced Nursing, 70*(9), 1970–1979. https://doi.org/10.1111/jan.12402

Stohler, N. A., Reinau, D., Jick, S. S., Bodmer, D., & Meier, C. R. (2019). A study on the epidemiology of tinnitus in the United Kingdom. *Clinical Epidemiology, 11*, 855–871. https://doi.org/10.2147/CLEP.S213136

Suzuki, N., Oishi, N., & Ogawa, K. (2019). Validation of the Japanese version of the tinnitus functional index (TFI). *International Journal of Audiology*, *58*(3), 167–173. https://doi.org/10.1080/14992027.2018.1534279

Sweetow, R. W., & Levy, M. C. (1990). Tinnitus severity scaling for diagnostic/therapeutic usage. *Hearing Instruments*, 41, 44-46.

Taylor, S. J., Bogdan, R., & DeVault, M. (2017). *Introduction to qualitative research methods: A guidebook and resource* (4th ed.).

Teggi, R., Cangiano, I., Familiari, M., Gioffrè, V., Nobile, A., & Gatti, O. (2025). The Tinnitus Handicap Inventory Total Score: what really counts? Experience on a sample of 1156 patients. *Audiology Research*, *15*(1). https://doi.org/10.3390/audiolres15010004

Terwee, C. , Prinsen, C. , Chiarotto, A. , Cw De Vet, H. , Bouter, L. , Marjan, JA. , Donald, W. , Patrick, L. , Mokkink, L. , & Terwee, C. (2018). *COSMIN methodology for assessing the content validity of PROMs User manual version 1.0*. www.cosmin.nl

Williamson, P. R., Altman, D. G., Blazeby, J. M., Clarke, M., Devane, D., Gargon, E., & Tugwell, P. (2012). Developing core outcome sets for clinical trials: Issues to consider. *Trials*, *13*. https://doi.org/10.1186/1745-6215-13-132

Theodoroff, S. M. (2015). Experimental use of transcranial magnetic stimulation (TMS) to treat tinnitus in a deaf patient. *Clinical Medical Reviews and Case Reports*, 2, 023. https://doi.org/10.23937/2378-3656/1410023

Todt, I., Rademacher, G., Mutze, S., Ramalingam, R., Wolter, S., Mittmann, P., et al. (2015). Relationship between intracochlear electrode position and tinnitus in cochlear implantees. Acta Oto-Laryngologica, 135, 781–785. https://doi.org/10.3109/00016489.2015.1024332

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., … Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine, 169*(7), 467–473. https://doi.org/10.7326/M18-0850

Trochidis, I., Lugo, A., Borroni, E., Cederroth, C. R., Cima, R., Kikidis, D., Langguth, B., Schlee, W., & Gallus, S. (2021). Systematic review on healthcare and societal costs of tinnitus. *International Journal of Environmental Research and Public Health, 18*(13). https://doi.org/10.3390/ijerph18136881

Tsukada, K., Nishio, S., & Usami, S. (2010). A large cohort study of GJB2 mutations in Japanese hearing loss patients. *Clinical Genetics, 78*(5), 464–470. https://doi.org/10.1111/j.1399-0004.2010.01407.x

Tunkel, D. E., Bauer, C. A., Sun, G. H., Rosenfeld, R. M., Chandrasekhar, S. S., Cunningham, E. R., Archer, S. M., Blakley, B. W., Carter, J. M., Granieri, E. C., Henry, J. A., Hollingsworth, D., Khan, F. A., Mitchell, S., Monfared, A., Newman, C. W., Omole, F. S., Phillips, C. D., Robinson, S. K., … Whamond, E. J. (2014). Clinical practice guideline: Tinnitus. *Otolaryngology - Head and Neck Surgery, 151*(2), S1–S40. https://doi.org/10.1177/0194599814545325

Turton, L., Souza, P., Thibodeau, L., Hickson, L., Gifford, R., Bird, J., Stropahl, M., Gailey, L., Fulton, B., Scarinci, N., Ekberg, K., & Timmer, B. (2020). Guidelines for best practice in the audiological management of adults with severe and profound hearing loss. *Seminars in Hearing, 41*(3), 141–245. https://doi.org/10.1055/s-0040-1714744

Turunen-Taheri, S., Carlsson, P. I., Ternevall, E., & Hellström, S. (2023). Mental Fatigue in Patients with Hearing Loss and/or Tinnitus Undergoing Audiological Rehabilitation—A Pilot Study. *Journal of Clinical Medicine*, *12*(21). https://doi.org/10.3390/jcm12216756

Tyler, R. S. (1995). Tinnitus in the profoundly hearing-impaired and the effects of cochlear implants. *Annals of Otology, Rhinology & Laryngology*, 104, 25–25.

Tyler, R. S., & Baker, L. J. (1983). Difficulties experienced by tinnitus sufferers. *Journal of Speech and Hearing Disorders, 48*(2), 150–154. https://doi.org/10.1044/jshd.4802.150

Tyng, C. M., Amin, H. U., Saad, M. N. M., & Malik, A. S. (2017). The influences of emotion on learning and memory. In *Frontiers in Psychology* (Vol. 8, Issue AUG). Frontiers Media S.A. https://doi.org/10.3389/fpsyg.2017.01454

Van de Heyning, P., Gavilán, J., Godey, B., Hagen, R., Hagr, A., Kameswaran, M., Li, Y., Manoj, M., Mlynski, R., O'driscoll, M., Pillsbury, H., Raine, C. H., Rajan, G., Schmutzhard, J., & Staecker, H. (2022). Worldwide Variation in Cochlear Implant Candidacy. *Journal of International Advanced Otology, 18*(3), 196–202. https://doi.org/10.5152/iao.2022.21470

van der Wal, A., Michiels, S., De Pauw, J., Jacxsens, L., Chalimourdas, A., Gilles, A., Braem, M., van Rompaey, V., Van de Heyning, P., & De Hertogh, W. (2022). ICF domains covered by the Tinnitus Questionnaire and Tinnitus Functional Index. *Disability and Rehabilitation*, *44*(22), 6851–6860. https://doi.org/10.1080/09638288.2021.1972172

van Zon, A., Smulders, Y. E., Ramakers, G. G., Stegeman, I., Smit, A. L., Van Zanten, G., et al. (2016). Effect of unilateral and simultaneous bilateral cochlear implantation on tinnitus: A prospective study. *Laryngoscope,* 126, 956–961. https://doi.org/10.1002/lary.25493

Veile, A., Zimmermann, H., Lorenz, E., & Becher, H. (2018). Is smoking a risk factor for tinnitus? A systematic review, meta-analysis and estimation of the population attributable risk in Germany. *BMJ Open, 8*(2). https://doi.org/10.1136/bmjopen-2017-016589

Velonaki, V. S., Kampouroglou, G., Velonaki, M., Dimakopoulou, K., Sourtzi, P., & Kalokerinou, A. (2015). Nurses' knowledge, attitudes and behavior toward Deaf patients. *Disability and Health Journal, 8*(1), 109–117. https://doi.org/10.1016/j.dhjo.2014.08.005

Verpy, E., Leibovici, M., Michalski, N., Goodyear, R. J., Houdon, C., Weil, D., Richardson, G. P., & Petit, C. (2011). Stereocilin connects outer hair cell stereocilia to one another and to the tectorial membrane. *Journal of Comparative Neurology, 519*(2), 194–210. https://doi.org/10.1002/cne.22509

Wallhäusser-Franke, E., Brade, J., Balkenhol, T., D'Amelio, R., Seegmüller, A., & Delb, W. (2012). Tinnitus: Distinguishing between subjectively perceived loudness and tinnitus-related distress. *PLoS ONE, 7*(4). https://doi.org/10.1371/journal.pone.0034583

Warren, R. L., & Fridberger, A. (2015). The basilar membrane acts as a passive support structure at the cochlear apex. *AIP Conference Proceedings, 1703*. https://doi.org/10.1063/1.4939340

Watts, E. J., Fackrell, K., Smith, S., Sheldrake, J., Haider, H., & Hoare, D. J. (2018). Why Is

Tinnitus a Problem? A Qualitative Analysis of Problems Reported by Tinnitus Patients. *Trends in Hearing, 22*. https://doi.org/10.1177/2331216518812250

Wells, T. S., Rush, S. R., Nickels, L. D., Wu, L., Bhattarai, G. R., & Yeh, C. S. (2020). Limited health literacy and hearing loss among older adults. *Health Literacy Research and Practice, 4*(2), e129–e137. https://doi.org/10.3928/24748307-20200511-01

Wilson, P. H., Henry, J., Bowen, M., & Haralambous, G. (1991). Tinnitus Reaction Questionnaire. *Journal of Speech, Language, and Hearing Research*, *34*(1), 197–201. https://doi.org/10.1044/jshr.3401.197

Wilson, P. H., & Henry, J. L. (1998). Tinnitus Cognitions Questionnaire: development and Psychometric properties of a measure of dysfunctional cognitions associated with tinnitus. In *International Tinnitus Journal* (Vol. 4, Issue 1).

Wheeler, S. L. & Hopwood, A.G. (2015). Tinnitus: A deaf hearing phenomenon. *Qualitative Inquiry,* 21, 173–174. https://doi.org/10.1177/1077800414542700

Wingard, J. C., & Zhao, H. B. (2015). Cellular and deafness mechanisms underlying connexin mutation-induced hearing loss – A common hereditary deafness. *Frontiers in Cellular Neuroscience, 9*. https://doi.org/10.3389/fncel.2015.00202

World Health Organization. (2023). *Deafness and hearing loss* https://www.who.int/health-topics/hearing-loss

World Health Organization. (2021). *World report on hearing* https://apps.who.int/iris/handle/10665/339913

Yang, C. H., Schrepfer, T., & Schacht, J. (2015). Age-related hearing impairment and the triad of acquired hearing loss. *Frontiers in Cellular Neuroscience, 9*. https://doi.org/10.3389/fncel.2015.00276

Yang, H., Cheng, G., Liang, Z., Deng, W., Huang, X., Gao, M., & Zheng, Y. (2021)

Efficacy of repetitive transcranial magnetic stimulation (rTMS) for tinnitus: a retrospective study. *Ear, Nose & Throat Journal*, 102(10), NP506–NP510. https://doi.org/10.1177/01455613211016896

Zahnert, T. (2011). Differenzialdiagnose der schwerhörigkeit. *Deutsches Arzteblatt, 108*(25), 433–444. https://doi.org/10.3238/arztebl.2011.0433

Zakzouk, S. (2002). Consanguinity and hearing impairment in developing countries: a custom to be discouraged. *The Journal of Laryngology & Otology, 116*(1), 1–4.

Zamanzadeh, V. , Rassouli, M. , Abbaszadeh, A. , Alavi Majd, H. A., Nikanfar, A. &, & Ghahramanian, A. (2014). Details of content validity and objectifying it in instrument development.
http://npt.tums.ac.ir

Zarenoe, R., & Ledin, T. (2013). A cohort study of patients with tinnitus and sensorineural hearing loss in a Swedish population. *Auris Nasus Larynx, 40*(1), 41–45.
https://doi.org/10.1016/j.anl.2012.05.005

Zeman, F., Koller, M., Schecklmann, M., Langguth, B., Landgrebe, M., Figueired, R., Aazevedo, A., Rates, M., Binetti, C., Elgoyhen, A. B., De Ridder, D., Vanneste, S., Staudinger, S., Frank, E., Kreuzer, P. M., Ppl, T. B., & Lehner, A. (2012). Tinnitus assessment by means of standardized self-report questionnaires: Psychometric properties of the Tinnitus Questionnaire (TQ), the Tinnitus Handicap Inventory (THI), and their short versions in an international and multi-lingual sample. *Health and Quality of Life Outcomes*, *10*.
https://doi.org/10.1186/1477-7525-10-128

Zhang, H., Ji, L., Wang, L., Yin, Z., Cen, J., & Guo, Y. (2023). Clinical characteristics and psychoacoustic analysis of acute and chronic subjective tinnitus. *Laryngoscope Investigative Otolaryngology, 8*(2), 546–553.
https://doi.org/10.1002/lio2.1037

Zheng, W., & Holt, J. R. (2021). The Mechanosensory Transduction Machinery in Inner Ear Hair Cells. *Annual Review of Biophysics, 50*, 43–65.
https://doi.org/10.1146/annurev-biophys-062420

Zohrabi, M. (2013). Mixed method research: Instruments, validity, reliability and reporting findings. *Theory and Practice in Language Studies, 3*(2), 254–262. https://doi.org/10.4304/tpls.3.2.254-262