ADULT PATIENTS WITH SEVERE-TO-PROFOUND HEARING IMPAIRMENT

A CLINICAL, REGISTER-BASED, AND INTERVIEW STUDY

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A CLINICAL, REGISTER-BASED, AND INTERVIEW STUDY

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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and Language Pathology
To my dear husband Masoud Taheri

Time, which includes our coming and going,
Has no known beginning nor end.
No one can tell the truth in this matter:
Where do we come from and where do we go?
by Omar Khayyam, Persia

To our sons Armin and Adrian, and to Greta, and grandchildren Astrid and Theodor

To my brother Sasu Turunen and his wife Minna

To the memory of our parents

Mieleni minun tekevi, aiveni ajattelevi lähteäni laulamahan,
saanisanehomaan, sukuvirtä scultamahan, lajivirtä laulamahan.
Sanat suussani sulevat, puhe et putelevat,
kielelseni kärkiövät, hampahilveni hajeevät
Kalevala, Karelia National Epic, by Elias Lönnrot, Finland
ADULT PATIENTS WITH SEVERE-TO-PROFOUND HEARING IMPAIRMENT. A CLINICAL, REGISTER-BASED, AND INTERVIEW STUDY

Satu Turunen-Taheri

ABSTRACT

In Sweden, roughly 25,000 individuals in the adult population have severe-to-profound hearing impairment, a prevalence rate of 0.2-0.3%. This patient group often needs extended audiological rehabilitation. The general aim of the thesis was to explore and describe patients with severe-to-profound hearing loss and/or patients with dual sensory loss. The specific focus studied was dual sensory loss in Paper I and Paper V, audiological rehabilitation in Papers I-V, cochlear implants (CI) in Paper III, and mental fatigue Paper IV. The five papers are based on data from the quality register for severe-to-profound hearing loss (Papers I-III), a pilot clinical study (Paper IV), and an interview study (Paper V). Paper I compared patients with dual sensory loss to patients with severe-to-profound hearing loss only and found a significant negative effect on QoL parameters among the dual sensory loss group. In Paper II, data on 4,286 patients with severe-to-profound hearing loss were studied. The results revealed that only 40.5% received extended rehabilitation. Furthermore, significantly more women than men received audiological rehabilitation. Hearing loss seemed to have a significantly more negative impact on daily life of women than of men. In particular, group rehabilitation and visits to a pedagogue seemed to have an important role in the experience of benefits in rehabilitation. In Paper III comparisons with patients rehabilitated with or without CI were investigated. The study found that only 8.5% had CI, despite most fulfilled the criteria for CI. The various reasons were studied, and the most common were related to hearing (management with hearing aids) and unknown reasons for not receiving CI. Paper IV indicated that most patients in the study population with severe mental fatigue had normal hearing or mild-to-moderate hearing loss, and severe mental fatigue was associated with severe tinnitus. Paper V demonstrated experiences of disabilities in daily life in patients with dual sensory loss. The results revealed that patients did not think of their dual sensory loss as a combination, but rather as separate disabilities. Isolation and the ability to control one’s own daily life emerged as the main themes. In conclusion, patients with dual sensory loss seemed to have a higher risk of experiencing difficulties in health conditions than patients with severe-to-profound hearing loss only. Individuals with dual sensory loss experienced a lack of control and isolation. Hearing loss seemed to have a more negative impact on women’s daily lives. For patients with severe-to-profound hearing loss, it is of great importance to be able to participate in interdisciplinary rehabilitation program. There is a need to highlight mental fatigue to focus on implementing guidelines for intervention and treatment in patients with hearing loss and/or tinnitus. Keywords: Swedish quality register, dual sensory loss, deafblindness, tinnitus, QoL, audiological rehabilitation, gender, cochlear implants, mental fatigue, qualitative interview
SAMMANFATTNING

I Sverige är den uppskattade prevalensen för vuxna med grav hörhinder cirka 25 000 individer, d.v.s. 0,2–0,3%. Denna patientgrupp behöver ofta utökad audiologisk rehabilitering. Det övergripande syftet med avhandlingen var att utforska och beskriva patienter med grav hörnedsättning och/eller patienter med dubbla sensoriska funktionshinder, dvs. grav hörsl- och synnedsättning, även kallad dövblindhet. Det specifika fokus som studerades var grav hörsl- och synnedsättning i Delstudie I och Delstudie V, audiologisk rehabilitering i Delstudier I-V, kokleaimplantat i Delstudie III och mental trötthet i Delstudie IV. De fem delarna i avhandlingen baseras på data från nationellt kvalitetsregistret för grav hörnedsättning vuxna (Delstudier I-III), en pilotstudie (Delstudie IV), och en intervjustudie (Delstudie V). I Delstudie I jämfördes patienter med grav syn- och hörnedsättning med patienter som endast hade grav hörnedsättning och vi fann signifikant negativ påverkan på livskvalitén i gruppen med dubbla funktionshinder. I Delstudie II studerades 4286 patienter med grav hörnedsättning. Resultaten visade att endast 40,5% fick utvidgad rehabilitering, och att betydligt fler kvinnor än män erhållit audiologisk rehabilitering. Dessutom indikerade resultaten att hörnedsättningen hade betydligt mer negativ inverkan på vardagen hos kvinnor än hos män. Grupprehabilitering och besök hos en pedagog var viktiga insatser för hur nöjda patienterna var med rehabiliteringen. I Delstudie III undersöktes patienter som var rehabiliterade med eller utan CI och studien visade att endast 8,5% hade CI i kvalitetsregistret. Orsakerna till att patienterna inte hade CI studerades och de två vanligaste orsakerna var hörerskäl (klarar sig bra med hörapparater och tekniska hjälpmedel) och okänt skäl till att patienterna inte rehabiliterats med CI. Resultaten i Delstudie IV indikerade att de flesta patienter med svår mental trötthet i studien hade normal hörsl eller mild till måttlig hörnedsättning, och svår mental trötthet var associerad med svår tinnitus. I Delstudie V studerades erfarenheter av funktionshinder i det dagliga livet hos patienter med både grav syn- och hörnedsättning. Resultaten visade att många patienter inte tänkte på sina dubbla funktionshinder som en kombination, snarare som en grav hörnedsättning och en grav synnedsättning separat. Isolering och förmåga att kontrollera sitt eget dagliga liv framkom som huvudteman. Sammanfattningsvis tycktes patienter med dubbla sensoriska funktionshinder ha högre risk att uppleva svårigheter vid olika hälsotillstånd än patienter med endast grav hörnedsättning. Individer med dubbla funktionshinder upplevde bristande kontroll och isolering. Hörnedsättning tycktes ha mer negativ inverkan på kvinnors vardag. För patienter med grav hörnedsättning är det är av stor vikt att kunna delta i ett tvärvetenskapligt rehabiliteringsprogram. Det finns ett behov av att belysa mental trötthet och fokusera på att implementera riktlinjer för intervention och behandling hos patienter med hörnedsättning och/eller tinnitus.

Nyckelord: Svensk kvalitetsregister, hörnedsättning, dubbla sensoriska funktionshinder, dövblindhet, tinnitus, livskvalitet, audiologisk rehabilitering, kön, kokleaimplantat, mental trötthet, kvalitativa intervju


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LIST OF ABBREVIATIONS

AED  Astheno-Emotional Disorder  
AMD  Age-related Macular Degeneration 
CI  Cochlear Implants 

dB HL  Decibel Hearing Level 
Deafblind-team unit  The Counselling and Support team  

EuroQoL-5D-3L/EQ5D  Standardized Health Questionnaire  
HADS  The Hospital Anxiety and Depression Scale  
Hz  Hertz 
ICF  The International Classification of Functioning, Disability and Health  

IHCs  Inner Hear Cells  
MFS  A self-reporting Mental Fatigue Scale  

NIDCD  The National Institute of Deafness and Other Communication Disorders  
OHCs  Outer Hear Cells  

Q-ORL  The Swedish Quality Register of Otorhinolaryngology  
(Nationellt kvalitetsregister för öron-, näs- och halssjukvård)  

PIRS  A self-rating instrument Problems Impact Rating Scale  

PTA  Pure-Tone Audiometry/Average 
PTA4  PTA for four frequencies (500, 1000, 2000 and 4000 Hz)  

QoL  Quality-of-Life  
RP  Retinitis Pigmentosa 

TBI  Traumatic Brain Injury 

THI  The Tinnitus Handicap Inventory 

USH  Usher Syndrome  

WHO  World Health Organization
1 INTRODUCTION

Hearing is a sense of utmost importance in communication. In 2019, hearing loss was the third leading cause of years lived with a disability (GBD, 2021a). Globally, hearing loss affects more than 1.5 billion people with a mild degree of hearing loss; an estimated 370 million people have moderate-to-severe hearing loss and 60 million people have severe-to-complete hearing loss in the better ear (WHO, 2021b). Hearing loss may also have significant negative effect on quality-of-life (QoL) when untreated (GBD, 2021a).

A combination of various degrees of dual sensory loss, affecting hearing and vision, i.e., deafblindness, influences even more daily functioning and communication (Heine & Browning, 2002). Deafblindness is estimated to affect 0.2–2% of the global population (WFDB, 2018). A review of 54 articles (Jaiswal et al., 2018) indicates difficulties in daily life functioning and mobility, social isolation, and communication problems affecting social interaction for patients with deafblindness.

Fatigue with various chronic health conditions is common and may negatively affect QoL. Hearing impairment may increase the risk for subjective fatigue (Hornsby et al., 2016). Mental fatigue is often described as an “early exhaustion after physical or mental activity, developing during mental activity” (Staub & Bogousslavsky, 2001). Thus, fatigue is a complex and multidimensional symptom, which makes it difficult to qualify and estimate the prevalence (Hornsby et al., 2016).

This thesis focuses on adult patients with severe-to-profound hearing loss and the effects of dual sensory loss, affecting both hearing and vision. The overall aim was to investigate the quality of audiological rehabilitation for these patient groups and whether audiological rehabilitation is equal across the country. A second aim was to investigate mental fatigue caused by hearing loss and/or tinnitus. A further aim was to highlight deafblind persons’ experiences and factors influencing their daily lives with both hearing and vision impairment.
2 BACKGROUND

2.1 HEARING AND HEARING LOSS

Hearing is an important sense, and necessary in children’s ability to develop spoken language (Kuhl, 2004), speech perception and communication, and school education as well as to obtain employment (GBD, 2021a). It is a common statement that “we hear with our ears, but we listen with our brains” (Pichora-Fuller et al., 2016). Hearing loss thus affects several dimensions, and left untreated may lead to reduced QoL, and social isolation (Carlsson et al., 2011; Dalton et al., 2003; Mick et al., 2014) and an increased risk for anxiety and depression (Li et al., 2014).

2.1.1 Anatomy and physiology

The sound travels from the outer ear, through the ear canal and the eardrum to the middle ear and to the inner ear (Figure 1), to the central auditory system, and finally reaches the brain (Gelfand, 2001). The acoustic signal reaches the peripheral auditory system via the outer ear and the tympanic membrane/eardrum and converts into vibrations through the three ossicles in the middle ear: malleus, incus, and stapes (Figure 1).

Figure 1. Schematic peripheral auditory system. Drawing by Satu Turunen-Taheri.
The vibrations continue to the oval window and transform and transmit in the fluid-filled inner ear in the cochlea, creating a travelling wave. The cochlea is spiraled and consists of three ducts: scala vestibuli, scala media and scala tympani (Figure 2A). The organ of Corti is situated on the basilar membrane in the scala media and contains sensory cells, inner hair cells (IHCs) and outer hair cells (OHCs) (Figure 2B).

![Figure 2 (A and B). Cross section of the cochlea (A) and the structure of the organ of Corti (B) (From: Emanuel and Letowski, 2009, Hearing Science: Chapter 8, page 292, Figure 8-13). With permission from Wolters Kluwer Health 2021-05-28.](image)

The vibration makes the hair cells bend and stimulates ion channels on top of the stereocilia, and electrical impulses are sent to the auditory nerve. Soundwaves in the cochlea convert to electrical impulses and are transported into the auditory nerve via spiral ganglion neurons through the afferent pathway (mostly IHCs) to the brain stem and the brain. (Figure 3). The efferent pathway is opposite from the brainstem, mostly to OHCs in the cochlea (Gelfand, 2001; Pickles, 2013).
2.1.2 Diagnosis

Hearing is diagnosed with audiometric psychoacoustic measurements, and one of the methods is pure-tone audiometry (PTA), with air-conduction and bone-conduction testing. The method is a standardized, modified Hughson-Westlake method (Gelfand, 2001; SAME, 1983). The detection of thresholds for the lowest sound at various frequencies one can hear is called the hearing level (HL) in decibels (dB). Zero (0) dB HL refers to a hearing level of normal hearing in healthy young male persons 18-25 years old, determined by the International Standards Organization (ISO, 1961. rev 1987, rev 2003) using the average HL. Hearing tests examine frequencies, in following order: 1000, 1500, 2000, 3000, 4000, 6000, 8000, 1000 (re-test), 500, 250 and 125 Hertz (Hz), one ear at a time.

The WHO (1991, revised 2021) defined a grading system of the degree of hearing loss using the average of HL from four frequencies, i.e., PTA4 (500, 1000, 2000 and 4000 Hz) in the best ear (revised 2021, modified Table 1) (WHO, 2021a).
Table 1. Grades of hearing loss and related hearing experience \(^a\) (slightly modified table), reprinted with permission from World Report on Hearing, Chapter 1.3 Decline in Hearing Capacity, Table 1.3, Page 38, WHO, 2021, with request ID is: 385479, 2021-08-31.

<table>
<thead>
<tr>
<th>Grade</th>
<th>Hearing threshold (^b) in better ear, decibel (dB)</th>
<th>Hearing experience in a quiet environment for most adults</th>
<th>Hearing experience in a noisy environment for most adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal hearing</td>
<td>Less than 20 dB</td>
<td>No problem</td>
<td>No or minimal problem hearing sounds</td>
</tr>
<tr>
<td>Mild hearing loss</td>
<td>20 - &lt; 35 dB</td>
<td>Does not have problems</td>
<td>May have difficulty hearing conversational speech</td>
</tr>
<tr>
<td>Moderate hearing loss</td>
<td>35 - &lt; 50 dB</td>
<td>May have difficulty</td>
<td>Difficulty hearing and taking part in conversation</td>
</tr>
<tr>
<td>Moderately severe hearing loss</td>
<td>50 - &lt; 65 dB</td>
<td>Difficulty hearing conversational speech</td>
<td>Difficulty hearing most speech and taking part in conversation</td>
</tr>
<tr>
<td>Severe hearing loss</td>
<td>65 - &lt; 80 dB</td>
<td>Does not hear most conversational speech</td>
<td>Extreme difficulty hearing speech and taking part in conversation</td>
</tr>
<tr>
<td>Profound hearing loss</td>
<td>80 - &lt; 95 dB</td>
<td>Extreme difficulty hearing raised voices</td>
<td>Conversational speech cannot be heard</td>
</tr>
<tr>
<td>Complete or total hearing loss/deafness</td>
<td>95 dB or greater</td>
<td>Cannot hear speech and most environmental sounds</td>
<td>Cannot hear speech and most environmental sounds</td>
</tr>
</tbody>
</table>

\(^a\) The classification and grades are for epidemiological use and applicable to adults. The following points must be kept in mind while applying this classification:
- While audiometric descriptors (e.g., category, pure-tone average) provide a useful summary of an individual’s hearing thresholds, they should not be used as the sole determinant in the assessment of disability or the provision of intervention(s) including hearing aids or cochlear implants.
- The ability to detect pure tones using earphones in a quiet environment is not, in itself, a reliable indicator of hearing disability. Audiometric descriptors alone should not be used as the measure of difficulty experienced with communication in background noise, the primary complaint of individuals with hearing loss.

\(^b\) “Hearing threshold” refers to the minimum sound intensity that an ear can detect as an average of values at 500, 1000, 2000, 4000 Hz in the better ear (WHO, 2021).

2.1.3 Hearing loss

Hearing loss can be congenital or acquired and may occur at one or more different levels in the hearing system, in the outer or middle ear, inner ear or higher up in the central auditory pathways. There are different types of hearing loss depending on which part is affected.

These are classified as: conductive, sensorineural, or mixed hearing loss. Conductive hearing losses are caused by difficulties with sound transmission through the external and/or middle ear (Figure 1). Sensorineural hearing loss is located either in the inner ear (the cochlear), in the auditory nerve (the retrocochlear), or in the central auditory system (the central) (Figure
3). *Mixed* hearing loss is the combination of both conductive and sensorineural damage (Gelfand, 2001; Møller, 2006).

An increasing number of elderly people are subjected to age-related hearing loss, called presbyacusis, which may lead to daily life consequences such as isolation, and depression (Gates & Mills, 2005). Untreated hearing loss may increase the risk developing dementia later in life (Livingston et al., 2017). An estimation of the prevalence of presbyacusis in Europeans is approximately 28% for men and 23% for women by age 70, with a similar prevalence in the Swedish population (Hoff et al., 2018).

### 2.2 SEVERE-TO-PROFOUND HEARING LOSS

The definition of severe-to-profound hearing loss in adults in Sweden has previously been the limit with the average air-conduction hearing level at ≥70 dB HL TMV4 in the best ear, or that the maximum speech perception <50%. These limits are the same as the criteria for unilateral cochlear implants (Socialstyrelsen, 2011c). Approximately 0.2-0.3% of the Swedish population, roughly 25,000 individuals suffer from severe-to-profound hearing loss (ORL, 2020). The WHO revised the grading of hearing loss (WHO, 2021a) with a new grading of 65 dB HL for severe hearing loss. A new revision of the guidelines for severe-to-profound hearing loss may need to be processed to resemble the new WHO grading in Sweden.

Patients with severe-to-profound hearing impairment often need more than technical rehabilitation, e.g., medical, and psychosocial rehabilitation (Carlsson et al., 2015; Ringdahl & Grimby, 2000). In particular, group rehabilitation and rehabilitation with hearing pedagogues/educators provide greater benefits in terms of audiological rehabilitation for patients with severe-to-profound hearing impairment, in addition to various hearing health care specialists such as physicians, psychologists, welfare officers, and audiologists (S. Turunen-Taheri et al., 2019).
2.3 VISION AND VISION IMPAIRMENT

One can say that the eye is like a window on the world around us. The optic system consists, roughly described, of the eye, optic nerves, and brain. We can see near and far. The eye registers light waves through the cornea, iris, pupil and lens to retinal photoreceptors, rods and cones, and via the optic nerve to the visual cortex in the brain (Ygge, 2011). The eye examination includes pupil function, visual acuity test, ocular pressure, and ophthalmoscopy. The standard visual acuity test involves reading letters on a visual board that is placed four to six metres away. The classification of vision impairment including blindness is shown in Table 2, where 0.1-0.05 defines severe vision impairment and blindness ≤0.02. In Sweden, a decimal scale is usually used in which the visual acuity is specified from 0.1 and up, where the full visual acuity is 1.0 and blindness correlates to 0.0.

Table 2. Classification of vision impairment including blindness, World Health Organization (WHO) 2019. With permission from WHO to use the table below, with request ID is: 385597, 2021-09-08. Available from: https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/1103667651

<table>
<thead>
<tr>
<th>Category</th>
<th>Presenting distance visual acuity</th>
<th>Equal to or better than:</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 No vision impairment</td>
<td>6/12</td>
<td>6/17</td>
</tr>
<tr>
<td>1 Mild vision impairment</td>
<td>5/10 (0.5)</td>
<td>5/10 (0.5)</td>
</tr>
<tr>
<td>2 Moderate vision impairment</td>
<td>6/18</td>
<td>6/18</td>
</tr>
<tr>
<td>3 Severe vision impairment</td>
<td>3/10 (0.3)</td>
<td>3/10 (0.3)</td>
</tr>
<tr>
<td>4 Blindness</td>
<td>6/50</td>
<td>6/50</td>
</tr>
<tr>
<td>5 Blindness</td>
<td>1/10 (0.1)</td>
<td>1/10 (0.1)</td>
</tr>
<tr>
<td>6 Blindness</td>
<td>20/200</td>
<td>20/200</td>
</tr>
</tbody>
</table>

Globally, the prevalence of vision loss is estimated to be 940 million people, with 34.3 million people with blindness and 238.3 million people with moderate to severe vision impairment in 2015 (GBD, 2016). A recent study shows that this trend is increasing; a new estimation is that 43.3 million people are blind and 295 million people have moderate to
severe vision loss (GBD, 2021b). In Sweden, approximately 420,000 people had, by definition, some kind of vision difficulties in 2018 (SCB, 2018).

One common cause of vision impairment is age-related. In elderly people, glaucoma, cataracts, and age-related macular degeneration (AMD) are common causes of blindness. Glaucoma is an optic neuropathy with high pressure in the eye, cataracts are opacities of the lens, and AMD has an atrophic (dry) form and an exudative (wet) form (Gripp et al., 2002; Quigley, 2011; Zhang et al., 2015).

2.4 SEVERE-TO-PROFOUND HEARING LOSS IN COMBINATION WITH SEVERE VISION IMPAIRMENT – DUAL SENSORY LOSS/DEAFBLINDNESS

Deafblindness is a combination of hearing and vision disability (EU, 2004). The condition is commonly congenital or age-related. The loss can be of various degrees, which means that the person may have remnants of their hearing or vision left. The Nordic definition of deafblindness adopted by the Nordic Leadership Forum (FSDB, 2007), revised in Nordic Welfare Centre in 2018 (NVC., 2018), is:

“Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability.

Main implications: To varying degrees, deafblindness limits activities and restricts full participation in society. It affects social life, communication, access to information, orientation, and the ability to move around freely and safely. To help compensate for the combined vision and hearing impairment, especially the tactile sense becomes important”.

Deafblindness is a heterogeneous disease, and the most common cause is Usher syndrome (USH) (Moller, 2003; Sadeghi et al., 2013), which is an inherited (genetic) autosomal recessive disease with hearing loss at birth and progressive retinitis pigmentosa (RP). RP is a hereditary retinal disease with degeneration of the rod and cone photoreceptors (Hartong et al., 2006). USH is divided into three subtypes; types I, II and III, which include a combination of various degrees of hearing, vision, and balance impairment (Mathur & Yang, 2015; Moller et al., 1989). The onset and regression of hearing and sight loss vary (Sadeghi et
A more rare disease is the autosomal recessive genetic syndrome called Alström’s disease, with early blindness and progressive hearing loss related to a severe metabolic disorder (Ronnasen et al., 2016).

Hearing and vision impairment affect communicative situations. Deafblindness reduces participation and inclusion in society on several levels. Vision and hearing loss may lead to decreased functioning in social life, while vision loss affects only to physical and mental health (Fischer et al., 2009). Environmental factors, such as participation in physical activities, can be negatively affected due to deafblindness in younger generations (Möller & Danermark, 2007). Communication difficulties due to vision loss and/or hearing loss in elderly people negatively affect social interaction and increases the risk for social isolation (Igarashi et al., 2021). Consequences for dual sensory loss may be isolation, social exclusion, effects on well-being, and a higher level of anxiety and depression compared to adult patients with severe-to-profound hearing loss only (Turunen-Taheri et al., 2017).

A review study including 54 studies on deafblindness demonstrated severe difficulties in communication with others, daily mobility and functioning (Jaiswal et al., 2018). Multiple impairments with a combination of dual sensory loss, and cognitive impairment (i.e., dementia) increase with age and lead to even more social isolation and reduced daily life activities compared with patients with dual sensory loss only (Guthrie et al., 2018).

### 2.5 TINNITUS

Tinnitus is a common auditory disorder and is described as the perception of sounds, e.g., ringing or rustling, in the absence of external auditory stimulation (Baguley et al., 2013). Tinnitus often occurs in combination and is related to hearing loss and exposure to noise or ototoxic drugs (Baguley et al., 2013; Eggermont & Roberts, 2004). Most studies indicate a prevalence between 10% and 15% in the adult population (Baguley et al., 2013). A reported total prevalence between 5.1% and 42.7% and an annoying tinnitus prevalence ranging from
3.0%–30.7% were shown in a systematic review (McCormack et al., 2016). The same study found an increase in age simultaneous with an increase in the prevalence of tinnitus, e.g., 40–50-year-olds with 11.2–25.0% prevalence and 70–80 years old with 15.0–31.7% prevalence. Severe tinnitus negatively affects cognitive functions (Andersson & McKenna, 2006) and health-related QoL (Nondahl et al., 2007).

2.6 NATIONAL QUALITY REGISTRY FOR SEVERE-TO-PROFOUND HEARING LOSS IN ADULTS

In Sweden, several national quality registers record and monitor Swedish health care with data from patients and professionals. The Swedish Quality Register of Otorhinolaryngology (Q-ORL, 1997) has nine sub-registers, one of which is the National Quality Registry for Severe-to-Profound Hearing Loss in Adults, founded in 2005. This quality registry provides, among other things, the opportunity to examine and evaluate how hearing care efforts work, examine regional differences, ensure the availability of equal care, and ensure the quality of rehabilitation in Sweden. The data in the register are presented at the group level. The inclusion criteria for the quality register are 70 dB HL (PTA4), and/or ≤ 50% on a speech recognition test, in the better ear (Q-ORL, 1997), which has been considered a relevant limit for severe hearing loss and is also the indicator used in Swedish medical indications for unilateral CI (Socialstyrelsen, 2011b).

2.7 SOCIAL FUNCTIONING, PSYCHOSOCIAL HEALTH, AND DISABILITY

The World Health Organization (WHO) describes health this way “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1946). Health is related to health status, functional status, and QoL (Guyatt et al., 1993; Patrick & Bergner, 1990). Having control and influence over one’s own living conditions promotes self-confidence and self-respect while a lack of self-control may restrict participation in society and increase feelings of powerlessness (Regeringskansliet., 2017).
The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) is a standard to measure diseases and disabilities in interaction in the context of health-related functioning. According to the WHO, the ICF can be used as a process model for functioning and disability in interactions between health conditions (WHO, 2001). A recent international validation study confirmed the validity of the brief ICF core set for hearing loss in adults (Karlsson et al., 2021).

Consequences of hearing loss can be related to poorer psychosocial health, trouble with cognitive functioning (Marrone et al., 2019), distress and depressed mood (Hallam et al., 2008). The assumed connection between hearing and dementia may occur via cognitive mechanisms and age-related changes in the brain (Pichora-Fuller et al., 2016; Pichora-Fuller et al., 2015). One hypothesis is that untreated hearing loss leads to isolation and later to dementia (Ralli et al., 2019). The association with hearing loss, hearing aids and ageing, as a stigma, is well-known (Hetu, 1996). Strategies to normalize and manage hearing loss are important, facilitating treatment and rehabilitation (Wallhagen, 2010). Depression in elderly individuals with hearing loss is common (Cosh et al., 2019), and a systematic review (Lawrence et al., 2020) of 35 studies showed that hearing loss increases the risk of depression.

Patients with hearing loss receiving audiological rehabilitation may obtain an opportunity to improve their social functioning, which in turn can improve their general health.

2.8 EXTENDED AUDIOLOGICAL REHABILITATION
The main purpose of aural/audiological rehabilitation is to improve hearing disability partly with technical rehabilitation including hearing aids, and with a combination of training and counselling to improve daily activity and participation, and QoL (Boothroyd, 2007). Patients can participate in hearing health care with audiological rehabilitation individually with multiple professional specialists, or in groups.
The person-centred model of audiological rehabilitation by Montano (Montano, 2014) emphasizes a focus on the patient by the keystone counselling, with the intervention of the patient’s history and self-assessment, communications strategies, technology, training and support. Hörselskadades Riksförbund (HRF) emphasizes the importance of the patient in the centre and shows their “rehabilitation wheel” with various interventions in hearing rehabilitation (HRF, 2017) (s. 29).

Extended audiological rehabilitation is commonly defined when a patient has received rehabilitation by at least three different professionals involved or participated in group rehabilitation (Carlsson, 2012). Extended rehabilitation may involve audiologists, physicians, psychologists, welfare officers, hearing rehabilitation pedagogues or technicians. The interdisciplinary audiological rehabilitation program should contain technical aids and medical, psychological, social, and educational programs for patients with severe-to-profound hearing impairment. Rehabilitation programs can broadly resemble, for example, “the Rehabilitation Wheel” at Karolinska University Hospital, Sweden (Figure 4).

Figure 4. The Rehabilitation Wheel, the unit of Extended Hearing Rehabilitation Rosenlund, Karolinska University Hospital, Sweden.
Participation in group rehabilitation can provide improvements in psychosocial aspects of health state related QoL, e.g., with counselling and training with communication strategies (Hawkins, 2005; Preminger, 2007; Preminger & Yoo, 2010; Öberg, 2017).

Extended audiological rehabilitation for patients with severe-to-profound hearing loss with group rehabilitation and rehabilitation by hearing pedagogues/educators were shown to have significant positive effects that benefit the whole rehabilitation process (S. Turunen-Taheri et al., 2019). Psychosocial consequences in terms of anxiety, depression, and sick leave are experienced to a greater degree among patients with severe-to-profound hearing loss compared to the general population (Carlsson et al., 2015). Carlsson et al (2015) suggested treatment with a focus on anxiety and depression early in rehabilitation. Audiological rehabilitation, including communication and coping strategies, improved mental health for elderly patients with hearing loss, anxiety, and depression (Cosh et al., 2019).

Backenroth & Ahlner (Backenroth & Ahlner, 2000) reported on QoL in a group of persons with moderate-to-severe hearing loss (n=30; mean age=49.1 years) who had participated in an audiological rehabilitation program at the Department of Audiology, Karolinska Hospital. It was shown that participants had benefitted from the program in that they learned different coping strategies for their life situations. Some conclusions of the study were ass follows: (1) audiological counselling interventions need to increase the focus on coping strategies and how the resources of the hearing-impaired person can be strengthened; (2) more focus must be placed on how audiological rehabilitation can support the individual’s work environment and actively enhance preventative measures at work; (3) involvement of family members in audiological counselling is necessary; and (4) more focus on psychosocial aspects could be beneficial as there is a recurrent need for counselling from a lifespan perspective (Backenroth & Ahlner, 2000). Finally, it is important to offer extended audiological rehabilitation for patients with severe-to-profound hearing loss for a good social functioning, psychosocial health and QoL.
2.9 AUDIOLOGICAL REHABILITATION WITH COCHLEAR IMPLANTS

The National Institute of Deafness and Other Communication disorders (NIDCD/NIH, 1988) describes cochlear implants (CIs) as electronic devices that can supply some form of hearing to an individual with severe-to-profound hearing loss or deafness. A CI consists of an outer and an inner part. The outer part, placed behind the ear, consists of a microphone, a speech processor, a transmitter, and a receiver and looks like a traditional hearing aid. The inner part, consisting of electrodes, is operated under the skin on the skull behind the ear and directed into the cochlea stimulating the spiral ganglion neurons.

Rehabilitation with binaural hearing, either with two CIs, or CI with hearing aid, for patients with severe-to-profound hearing loss improves speech tests compared with one CI only (Ciorba et al., 2019). In Sweden, despite fulfilling the national CI criteria, only 8.5% in the quality register were rehabilitated with CI (S. K. Turunen-Taheri, M. Edén, et al., 2019). In Sweden, approximately 3400 adults have received CI until 2020 (Bamplantorna, 2020).

Furthermore, significantly more women (56.5%) than men were rehabilitated with CI (S. K. Turunen-Taheri, M. Eden, et al., 2019).

2.10 MENTAL FATIGUE IN COMBINATION WITH HEARING LOSS AND/OR TINNITUS

Fatigue is difficult to define because it is a subjective phenomenon (Staub & Bogousslavsky, 2001), but it has a negative impact on QoL (Hornsby et al., 2016). Fatigue is complex and can be experienced in various dimensions e.g., general, physical, mental, emotional, and energy/vigour fatigue (Donovan et al., 2015; Stein et al., 2004). An earlier study (Lindqvist & Malmgren, 1993) presented a diagnostic classification for organic mental disorders, and one of these was astheno-emotional disorder (AED). Typical symptoms in AED include “an impaired concentration ability, memory difficulties, increased mental fatiguability, irritability and emotional instability” for patients with fatigue after traumatic brain injury (TBI) in connection with brain disorders such as brain tumours, infections and vascular diseases.
(Lindqvist & Malmgren, 1993). Similar symptoms for disabling fatigue in patients after suffering from a stroke are observed (Staub & Bogousslavsky, 2001). Patients with TBI reported a negative impact on QoL with poorer general health and a higher risk for social isolation and depression (Hawthorne et al., 2009).

Common symptoms for mental fatigue related to cognitive functioning are concentration and memory, stress intolerance, light and noise sensitivity or intolerance, and diminished sleep. A patient with mental fatigue will become mentally exhausted with an abnormally long recovery time after cognitive activity (Johansson & Rönnback, 2012), from which patients cannot rest (Johansson & Rönnbäck, 2014). There are diagnostic criteria for long-lasting mental fatigue. Diagnosis can partly be made using a self-reporting Mental Fatigue Scale (MFS) developed by Johansson et al. (Johansson et al., 2010), which was adapted from Rödholm et al. (Rödholm et al., 2001). The MFS contains 15 questions evaluating affective, cognitive, and sensory symptoms. The self-report MFS questionnaire has been used since 2011 in audiological rehabilitation for adult patients with hearing loss and/or patients with severe tinnitus at Karolinska University Hospital, Stockholm, Sweden. It was found that the MFS questionnaire contributes to more confident assessment of patients. MFS provides a detailed and accurate description of the patient’s complaints and the opportunity to follow the clinical course. Mental fatigue affects the ability to work, and patients often require sick leave to unload from work and to be able to rest from sound.

A systematic review of 20 studies (Holman et al., 2020) investigated the hypothesis that hearing aid fitting have an impact on fatigue, but they could not find significant evidence to support that, so more studies are needed in this area. A recent study determined that consequences of listening-related fatigue can have a negative effect on QoL for adult patients with hearing loss in physical, mental, emotional, and social dimensions (Davis et al., 2021).
A U.S. study (Moore et al., 2017) shows that long-standing auditory processing is associated with changes in brain activation and can cause mental fatigue over time. The presence of background noise negatively affects speech understanding for patients with hearing loss, resulting in communication difficulties (Moore, 2003) and leading to mental fatigue (Hornsby, 2013). A study by Jahncke and Halin (Jahncke & Halin, 2012) showed that patients with hearing impairment had higher levels of stress hormone and were more fatigued by noise exposure than patients with normal hearing.

The cause of extraordinary fatigue is not known. One hypothesis is that the symptom may be caused by reduced glutamate uptake capacity by the dysfunction of astrocytes, which is an important transport protein for glutamate at the cellular level (Rönnbäck & Hansson, 2004). Several studies (Brozoski et al., 2013; Prasad & Bondy, 2020) have shown that glutamate and increased levels of oxidative stress (Henderson et al., 2006; Prasad & Bondy, 2020) have an important role in progressive damage to the inner ear and the development of hearing loss.
3 AIMS

3.1 GENERAL AIMS
The overarching aim of this thesis was to explore the quality and usefulness of audiological rehabilitation for adult patients with severe-to-profound hearing loss, with or without severe vision impairment. Another aim was to investigate and describe which kind of audiological rehabilitation patients received, also from a gender perspective.

3.2 SPECIFIC AIMS
The specific aims of the following five studies were as follows:

Paper I To investigate demographic characteristics, received audiological rehabilitation and quality-of-life in adult patients with combined dual sensory loss, e.g., severe-to-profound hearing impairment and simultaneous severe vision impairment, in comparison with solely severe-to-profound hearing loss in Sweden.

Paper II To identify and investigate the various types and benefits of audiological rehabilitation in adult patients with severe-to-profound hearing impairment received in Sweden.

To examine hearing health care equality from a gender perspective.

Paper III To investigate the proportions of adult patients with severe-to-profound hearing impairment who had been rehabilitated with cochlear implants (CIs) in Sweden.

To investigate and analyse the reasons for not being investigated and treated with CI, despite meeting the criteria for CI.

To examine gender and age equality for this patient group.
**Paper IV**  
To identify and explore severe mental fatigue in adult patients with hearing loss and/or tinnitus in a population seeking audiological rehabilitation care in Stockholm, Sweden.

To examine the usefulness of a self-reported Mental Fatigue Scale (MFS) as a diagnostic instrument in these patient groups.

**Paper V**  
To describe daily life experiences of disabilities in adult patients with a combination of severe vision impairment and severe-to-profound hearing impairment.

To investigate which kinds of rehabilitation and support patients with dual sensory loss have received.
4  MATERIALS AND METHODS

4.1  STUDY DESIGN

Five studies are included in the present thesis. Four studies applied a quantitative, descriptive, retrospective approach, and the fifth study used a qualitative approach.

Three of these studies (Papers I-III) are based on data from the national quality register for severe-to-profound hearing loss in adults. The fourth study (Paper IV) is a clinical retrospective pilot study based on patients’ medical records and various questionnaires. The fifth study (Paper V) is an interview study in consecutive patients seeking care with dual sensory loss.

Table 3 shows an overview of the design, aims, study population, methods, and analysis in all five studies.

4.2  STUDY POPULATION

In Paper I, the study population consisted of 543 adult patients with severe vision impairment and severe-to-profound hearing loss among the 2,319 patients registered in the Swedish Quality Register of Otorhinolaryngology (Q-ORL) between 2006 and 2012.

In Paper II, the study is based on data from 4,286 adult patients with severe-to-profound hearing impairment registered in the Q-ORL from 2006 to 2015.

In Paper III, the study population consisted of 1,076 adult patients, of which 90 with CI and 986 without CI, from the Q-ORL from April 2015 to August 2017, on data from a new baseline questionnaire.

In Paper IV, the study population consisted of 76 patients with mild-to-severe mental fatigue symptoms between 2011 and 2017 from the Department of Audiology and Neurotology, Karolinska University Hospital, Stockholm, Sweden.
In Paper V, the study is based on 14 interviews of adult patients with severe vision impairment combined with severe-to-profound hearing impairment, in 2018-2019, seeking care at the Department of Audiology and Neurotology, Karolinska University Hospital and at the Counselling and Support team, called the Deafblind-team unit, Sabbatsberg Hospital, Stockholm, Sweden.

4.2.1 Inclusion criteria
The inclusion criteria for Papers I-III were the same as those in the Q-ORL as follows: 19 years or older, average hearing threshold at four frequencies (PTA4) of 70 dB HL or more in the best ear, or speech recognition test score worse than 50% in the better ear.

In Paper IV, the inclusion criteria were as follows: adult patients seeking care at the Department of Audiology and Neurotology, Karolinska University Hospital, who completed a self-reported Mental Fatigue Scale (MFS) questionnaire with a cut-off score of 10.5 or more.

The inclusion criteria for participants in Paper V were as follows: adult patients with severe-to-profound hearing impairment (PTA4) at 61 dB HL or more in the best ear (WHO, 1991) with a combination of severe vision impairment. Consecutive patients seeking care at the Department of Audiology and Neurotology, Karolinska University Hospital and at the Counselling and Support team for persons with deafblindness at Sabbatsbergs Hospital were included.
Table 3. Overview of Design, Aim, Materials, Included data and Analysis of the five Papers/studies (I-V).

<table>
<thead>
<tr>
<th>Paper</th>
<th>Design</th>
<th>Aim</th>
<th>Year/s</th>
<th>Materials</th>
<th>Data collection</th>
<th>Included data/Questionnaires</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Quantitative, retrospective</td>
<td>To investigate demographic characteristics, received audiological rehabilitation and quality-of-life of adult patients with combined dual sensory loss, e.g., severe-to-profound hearing impairment and simultaneous severe vision impairment, in comparison with patients with severe-to-profound hearing loss in Sweden.</td>
<td>2006-2012</td>
<td>Study population: 543 with dual sensory loss Age 19-96 Mean age 64.6 272 (50.1%) women</td>
<td>Register data</td>
<td>The general quality register questionnaire, EQ5D, PIRS, HADS</td>
<td>Chi-square test, Logistic regression with crude and adjusted OR, Unpaired t-tests, Age, Gender</td>
</tr>
<tr>
<td>II</td>
<td>Quantitative, retrospective</td>
<td>To identify and investigate the various types, and benefits of audiological rehabilitation adult patients with severe-to-profound hearing impairment received in Sweden. To examine hearing health care equality in gender perspective.</td>
<td>2006-2015</td>
<td>Study population: 4286 with severe-to-profound hearing loss Age 19-101 Mean age 69 2129 (49.7%) women</td>
<td>Register data</td>
<td>The general quality register questionnaire, and hearing thresholds, EQ5D, PIRS</td>
<td>Unpaired t-test, Chi-square test, Mean, median, standard deviations, percentages, Logistic regression analyses with crude and adjusted OR, Hosmer and Lemeshow test (Table 3), Median hearing thresholds</td>
</tr>
<tr>
<td>III</td>
<td>Quantitative, retrospective</td>
<td>To investigate how many adult patients with severe-to-profound hearing impairment were rehabilitated with cochlear implant (CI) in Sweden. To investigate and analyze reasons for not been investigated and treated with CI, despite the criteria for CI is fulfilled. To examine gender and age equality for this patient group.</td>
<td>24 April 2015 to 24 August 2017</td>
<td>Study population, total: 1076 with severe-to-profound hearing impairment Age 20-99 Mean age 70.6 480 (44.5%) women CI-group: 90 with CI Age 20-92 Mean age 62.9 51 (56.5%) women Reference group: 986 without CI Age 20-99 Mean age 71.3 429 (43.5%) women</td>
<td>Register data</td>
<td>The baseline questionnaire in the quality register and Estimation scale of hearing impact and TMV4</td>
<td>Unpaired t-tests, Chi-square tests, Mean, standard deviation, percentages, Logistic regression analyses, The Hosmer and Lemeshow test (Table 2)</td>
</tr>
<tr>
<td>IV</td>
<td>Quantitative, retrospective pilot</td>
<td>To identify and explore the severe mental fatigue in adult patients with hearing loss and/or tinnitus when seeking audiological rehabilitation care in Stockholm, Sweden. To examine the self-reported Mental Fatigue Scale (MFS) as a diagnostic instrument in these patient groups.</td>
<td>2011-2017</td>
<td>Study population: 76 patients with symptomatic mental fatigue (mild to severe MFS) Age 38-65 Mean age 52.5 53 (69.5%) women</td>
<td>Medical journal data, and Questionnaires</td>
<td>Hearing thresholds Questionnaires: Mental Fatigue Scale (MFS), Tinnitus Handicap Inventory (THI), The Hospital Anxiety and Depression Scale (HADS)</td>
<td>Unpaired t-tests Chi-square tests Mean, median, standard deviations, percentages</td>
</tr>
<tr>
<td>V</td>
<td>Qualitative</td>
<td>To describe daily life experiences of disabilities in adult patients with a combination of severe vision impairment and severe-to-profound hearing impairment. To investigate various kind of rehabilitation and support patients with dual sensory loss received.</td>
<td>2018-2019</td>
<td>Study population: 14 patients with dual sensory loss Age 48-81 Mean age 70.1 7 (50%) women</td>
<td>Individual interviews</td>
<td>Semi-structured interview guide Hearing thresholds (PTA4) and severe vision impairment for inclusion criteria</td>
<td>Inductive content analysis</td>
</tr>
</tbody>
</table>

*Total 2319 of whom 34 missing data about vision impairment.*
4.3 MATERIALS AND PROCEDURE

4.3.1 Data collection

4.3.2 Questionnaires, medical records, and interview guide
The first study (Paper I) compares patients with severe-to-profound hearing loss and patients with dual sensory loss, vision impairment and severe-to-profound hearing loss using the earlier general questionnaire and the complementary health questionnaire in a quality registry including EuroQoL-5D-3 L/EQ5D and a self-rating instrument PIRS-scale. The Hospital Anxiety and Depression Scale (HADS) was also used in the study. These questionnaires are described below.

The second study (Paper II) contains the same questionnaires as in Paper I except for HADS.

The third study (Paper III) used a new baseline questionnaire, including a new estimation scale (instead of the PIRS-scale).

The fourth study (Paper IV) included medical records with audiological data and a self-reported Mental Fatigue Scale (MFS) questionnaire, Tinnitus Handicap Inventory (THI), Hospital Anxiety and Depression Scale (HADS), and medical records with audiological data.

The fifth study (Paper V) used a semi-structured interview guide (Supplementary material) and medical records with audiological data.

4.3.2.1 The General questionnaire
The quality register for severe-to-profound hearing loss in adults used the general questionnaire and complementary health questionnaires between 2006-2015 (Papers I-II).
The general questionnaire included the following data: age, gender, heredity, marital status, education level, employment, sick leave, pure-tone audiometry results in the right and left ear (250 Hz-8000 Hz), specific diagnoses, debut of hearing loss, types of communication, vision impairment, other disabilities, use of hearing aid/s and/or CI, type of rehabilitation received, referral to a speech therapist or physiotherapist due to hearing loss, support from family, workplace and work management, benefits of hearing health care, and benefits of hearing aid/CI.

4.3.2.2  Complementary health questionnaire EuroQoL-5D-3 L/EQ5D
The standardized EQ5D instrument measures various aspects of health status, such as mobility, hygiene, usual activities, pain/discomfort, and anxiety/depression, with three levels: no, some or severe problems. An EQ5D score of 0.7 or less (Carlsson et al., 2015) indicates a negative impact on quality of life in Papers I-II.

4.3.2.3  Complementary Problems Impact Rating Scale (PIRS)
A self-rating instrument called the Problems Impact Rating Scale (PIRS) was used in Papers I-II. The scale measures how hearing impairment affects patients’ daily lives with a range between 0-100. A strong negative impact is defined as a score of 70 or higher (Carlsson et al., 2011).

4.3.2.4  The Hospital Anxiety and Depression Scale (HADS)
Paper I and Paper IV included a self-assessment HADS (Zigmond & Snaith, 1983), which contains seven items about anxiety and depression, respectively, with four alternatives in each statement (0-3). The study used the commonly used cut-off score value of 8 or more to determine negative levels of anxiety and depression (Bjelland et al., 2002).

4.3.2.5  A new Baseline questionnaire including Estimation scale
In 2015, a new baseline questionnaire and a follow-up questionnaire began to be used in the quality register. Paper III used this baseline questionnaire containing data such as age,
gender, PTA4, results of speech recognition tests, methods for communication, hearing aid/s and/or CI use, rehabilitation received, employment and sick leave. A self-rating scale measuring the impact of hearing impairment on daily life with a new ‘estimation scale’ rated from 0-100 was also used. Zero indicates no influence, and 100 indicates a maximum negative impact on the quality of daily life. The study used the same score of 70 or more for the estimation scale as for PIRS, indicating a strong negative impact on daily life (Carlsson et al., 2011).

4.3.2.6 Mental Fatigue Scale (MFS)

The self-assessment MFS contains 15 questions about symptoms evaluating affective, cognitive, and sensory problems with four levels (0–3). In Paper IV, a cut-off score of 10.5 was used as suggested in a previous study (Johansson & Rönnbäck, 2014).

4.3.2.7 Tinnitus Handicap Inventory (THI)

Paper IV included a validated, self-reported THI questionnaire (Newman et al., 1996) containing 25 questions with three levels (yes, sometimes, no) related to tinnitus and hearing problems measuring the severity and impact of tinnitus consequences on patients’ daily lives. The total score is classified into four handicap levels and a cut-off score is based on 57 points or more as a severe tinnitus handicap.

4.3.2.8 Interview guide

In Paper V, a semi-structured interview guide was used. Questions about background, duration of hearing and vision impairment, possible effects such as limitations on daily life, need for support, availability in society, technical aids, and thoughts about the future were asked (Supplementary material). Participants were given an opportunity to engage in open dialogue and discussions.
4.4 STATISTICAL ANALYSIS

For Papers I-IV, statistical analyses were conducted using Microsoft® Office Excel and IBM® SPSS® Statistics version 24.0 and 27.0. In Paper I, chi-square tests, unpaired \( t \)-tests, logistic regression models, and crude and adjusted models with a 5% significance level were used. The mean, standard deviation, and percentages were used. In Paper II, unpaired \( t \)-tests, chi-square tests, the mean, median, standard deviations, and percentages were used. Logistic regression analyses with crude and adjusted models, and Hosmer and Lemeshow tests for goodness-of-fit were used. Significance level was defined at 5%. In Paper III, chi-square tests, unpaired \( t \)-tests, the mean, standard deviation, and percentages were calculated. Logistic regression analyses with crude odds ratios for multiple regression analysis were used for analyzing the risk for the ‘unknown reasons for not having been rehabilitated with CI’ (Table 2) with the Hosmer and Lemeshow test for goodness-of-fit, with a significance level of 5%.

In Paper IV, \( t \)-tests, chi-square-tests, means, medians, standard deviations, and percentages were used. Mental fatigue scores were stratified by three levels (10.5–15, 15.5–20, \( \geq 20 \)) (Johansson & Rönnbäck, 2014). Pearson’s correlation analysis was added after the first review. In Paper V, all interviews were recorded, transcribed verbatim, analysed, and categorized with inductive content analysis with coding into categories and themes (Elo & Kyngas, 2008; Graneheim & Lundman, 2004; Krippendorff, 2013).

4.5 ETHICAL APPROVAL

The World Medical Association (WMA) Declaration of Helsinki: Ethical principles for medical research involving humans (WMA, 2013) has been considered in all processes of all five studies. The studies were approved by the Regional Ethics Committee, Uppsala, Dnr. 2012/057 (Paper I: regarding HADS) and by the Regional Ethical Ethics Committee, Stockholm, Dnr. 2014/2101-31 (Papers I-V).

For the register studies, Papers I-III, participants were informed about the quality register for adult patients with severe-to-profound hearing impairment during a visit to the hearing health
care facility at the hospital. The quality registers are based on the fact that broad consent is required, i.e., consent to participate in research in general rather than for specific studies. This means that participants must be informed about the register and that researchers are allowed to perform registered research without obtaining consent. Information can be both oral and written and many clinics have information about registry in waiting room. All data material from the registry is secured by decoded group-level data. Analyses were conducted on a group level.

All participants signed an informed consent form for participation in the clinical study (Paper IV) and in the interview study (Paper V). Participants were informed with written information about the studies, informed of confidentiality, and informed that they could cancel participation at any time without providing a reason and without affecting future care. In addition, oral information was given to all participants in the interview study (Paper V).

The original ethical application for Paper V, did not include approval to use citations; therefore, a new consent form applying the use of direct quotations from the interviews was signed by the participants. The interviews were taped, and the material was anonymized using codes.

According to ethical principles, some individuals and groups are especially vulnerable, i.e., they can be recognized by others. This concerns Paper V, in which only 14 participants with dual sensory loss participated. The researchers chose not to provide detailed information about each individual person in the study to avoid deducing this information to each of them. The transcribed text was sent to each of the participants to read through their own interviews. The importance and potential benefit of the study for this patient group were considered. The present research provides increased knowledge and can improve the quality of care for these patient groups.
5 RESULTS

This chapter presents a summary of the findings from Papers 1-V. For further details, see the reprinted publications for Papers I-III and manuscripts for Papers IV and V.

5.1 STUDY I

The results for the study presented in Paper I showed significant differences in demographic characteristics. Five hundred forty-three patients with dual sensory loss were younger (mean age), more likely lived alone and had a lower education level than 1,742 patients with severe-to-profound hearing loss only, referred to as the control group (Table 4).

| Table 4. Demographic characteristics in patients with dual sensory loss; vision impairment, and severe-to-profound hearing loss in comparison with patients with solely severe-to-profound hearing loss (Paper I). |
|---------------------------------|---------------------------------|---------------------------------|
| **Age (years),**                | **Vision and severe to profound hearing loss, n = 543, n (%)** | **Severe to profound hearing loss, n = 1742, n (%)** | **p-value** |
| **Gender**                      | **Mean (SD)**                  | **Mean (SD)**                  | **ns** |
| Women                           | 64.6 (17.8)                    | 66.5 (17.8)                    | <0.05 |
| Civil status                    | **Gender**                     | **Gender**                     | **ns** |
| Living alone                    | 350 (64.5%)                    | 958 (55%)                      | <0.001 |
| Age groups (years)              | **Age groups (years)**         | **Age groups (years)**         | **p-value** |
| 19–40                           | 35 (6%)                        | 188 (11%)                      | <0.001 |
| 41–60                           | 70 (13%)                       | 363 (21%)                      |        |
| 61–80                           | 188 (35%)                      | 741 (42%)                      |        |
| 81–110                          | 248 (46%)                      | 450 (26%)                      |        |
| Education                       | **Education**                  | **Education**                  | **p-value** |
| Elementary school               | 281 (55.5%)                    | 692 (42%)                      | <0.001 |
| Training school                 | 16 (3%)                        | 71 (4%)                        |        |
| High school                     | 96 (19%)                       | 471 (28%)                      |        |
| Other education                 | 91 (10.5%)                     | 251 (11%)                      |        |
| University                      | 53 (12%)                       | 180 (15%)                      |        |

*All p-values calculated with chi-square test except age where unpaired t-test is performed.

The findings also revealed a significant negative effect on QoL outcomes and on HADS-anxiety and HADS-depression, as evidenced by the EQ5D and PIRS scores in patients with dual sensory loss compared with patients with severe-to-profound hearing loss (Table 5).
Table 5. The proportion of patients, crude (%), and adjusted odds-ratios (Ors) with 95% confidence intervals (CI) for different QoL outcomes comparing patients with dual sensory loss; vision impairment with severe-to-profound hearing loss (dual sensory loss) and severe-to-profound hearing loss (HL) (Paper I).

<table>
<thead>
<tr>
<th></th>
<th>IIADS anxiety ≥8 n (%)</th>
<th>IIADS depression ≥8 n (%)</th>
<th>EQCD &lt; 0.7 n (%)</th>
<th>PIES ≥70 n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dual sensory loss</td>
<td>190 (41%)</td>
<td>84 (34%)</td>
<td>206 (45%)</td>
<td>113 (59%)</td>
</tr>
<tr>
<td>Severe to profound HL</td>
<td>268 (25%)</td>
<td>180 (19%)</td>
<td>385 (24%)</td>
<td>529 (36%)</td>
</tr>
</tbody>
</table>

Crude OR (95% CI), p-value: 1.70 (1.17-2.48), p<0.001; 2.18 (1.56-2.97), p<0.001; 2.57 (2.07-3.20), p<0.001; 1.76 (1.41-2.18), p<0.001.

Adjusteda OR (95% CI), p-value: 1.87 (1.36-2.57), p<0.001; 2.38 (1.70-3.31), p<0.001; 2.30 (1.82-2.90), p<0.001; 1.80 (1.42-2.27), p<0.001.

*OR adjusted for gender, civil status, age classes and education.

The study found that few patients receive extended audiological rehabilitation, with only three of 10 patients (32%) with dual sensory loss and 40% of patients with severe-to-profound hearing loss. More women than men received extended audiological rehabilitation, 58% and 42%, respectively, in the dual sensory loss group. The same results were revealed in the control group, with 55% women and 45% men.

The number of patients with hearing aids and CI did not differ significantly between study groups.

5.2 STUDY II

The study, in Paper II, presented demographic data from 18 of 21 Swedish county councils of 4,286 patients with severe-to-profound hearing impairment. Women were slightly younger (mean age) and lived alone significantly more than men. Only 40.5% of the total study population received extended audiological rehabilitation, of which significantly more women (54.5%) did than men. Women received group rehabilitation, communication rehabilitation (e.g., sign language, sign support language, lips-reading training, hearing tactics) in a group, and visited technicians, welfare officers, hearing rehabilitation educators/pedagogues, psychologists and physicians significantly more often compared to men (Table 6).

In general, 9 out of 10 patients (88%) received a “good/very good” benefit from audiological rehabilitation. Group rehabilitation and rehabilitation with a hearing rehabilitation...
educator/pedagogue were two of the methods that resulted in the most significant benefits (Table 7).

Table 6. The proportion of patients with severe-to-profound hearing loss in audiological rehabilitation with various hearing care professionals in Sweden with the proportions of male and female patients, crude odds ratios (OR) with 95% confidence intervals (CI) comparing gender differences (Paper II).

<table>
<thead>
<tr>
<th>Severe-to-profound hearing loss in Sweden</th>
<th>n=4386, n (%)</th>
<th>Male n=2157</th>
<th>Female n=2129</th>
<th>Crude OR (95% CI)</th>
<th>p-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group rehabilitation†</td>
<td>411 (9.5)</td>
<td>167 (40.5)</td>
<td>244 (59.5)**</td>
<td>1.54 (1.25-1.89)**</td>
<td>0.000</td>
</tr>
<tr>
<td>Audiologist</td>
<td>417 (9.4)</td>
<td>2107 (50.5)</td>
<td>2068 (49.5)</td>
<td>0.80 (0.55-1.17)</td>
<td>0.259</td>
</tr>
<tr>
<td>Technician</td>
<td>1147 (27)</td>
<td>531 (46.5)</td>
<td>616 (53.5)**</td>
<td>1.24 (1.08-1.42)**</td>
<td>0.001</td>
</tr>
<tr>
<td>Welfare officer</td>
<td>783 (18.3)</td>
<td>349 (44.3)</td>
<td>434 (35.3)**</td>
<td>1.32 (1.13-1.52)**</td>
<td>0.000</td>
</tr>
<tr>
<td>Hearing rehabilitation educator</td>
<td>1507 (35)</td>
<td>700 (46.5)</td>
<td>807 (53.5)**</td>
<td>1.27 (1.12-1.44)**</td>
<td>0.000</td>
</tr>
<tr>
<td>Psychologist</td>
<td>154 (3.5)</td>
<td>47 (30.5)</td>
<td>107 (69.5)**</td>
<td>2.37 (1.67-3.36)**</td>
<td>0.000</td>
</tr>
<tr>
<td>Physician</td>
<td>1103 (25.5)</td>
<td>503 (45.5)</td>
<td>600 (54.5)**</td>
<td>1.29 (1.12-1.48)**</td>
<td>0.000</td>
</tr>
<tr>
<td>Communication rehabilitation in groups‡</td>
<td>427 (16)</td>
<td>153 (35.5)</td>
<td>275 (64.5)**</td>
<td>1.05 (1.08-1.40)**</td>
<td>0.000</td>
</tr>
<tr>
<td>Referral speech therapist</td>
<td>116 (2.5)</td>
<td>39 (31)</td>
<td>77 (69)</td>
<td>0.97 (0.77-1.21)</td>
<td>0.907</td>
</tr>
<tr>
<td>Referral physiotherapist</td>
<td>49 (1)</td>
<td>18 (36.7)</td>
<td>31 (63.3)</td>
<td>1.75 (0.97-3.14)</td>
<td>0.056</td>
</tr>
<tr>
<td>Extended audiological rehabilitation§</td>
<td>1734 (40.5)</td>
<td>788 (45.5)</td>
<td>946 (54.5)**</td>
<td>1.38 (1.22-1.57)**</td>
<td>0.000</td>
</tr>
</tbody>
</table>

* p<.05; ** p<.01; *** p<.001
† with various hearing care professionals involved in.
‡ e.g. sign language, sign support language, training for lips-reading, hearing tactics
§ participated in a group rehabilitation or rehabilitated at least with three different specialists.

Table 7. The benefit of various audiological rehabilitation efforts for patients who participated/not participated for group rehabilitation and/or visits to the multiple professional competencies, calculated with “None/Some” benefits, for patients with severe-to-profound hearing impairment in Sweden, logistic regression analyses with crude and adjusted odds ratios (OR) with 95% confidence intervals (CI). For logistic regression Hosmer and Lemeshow Test shows goodness-of-fit 0.315 (Paper II).

<table>
<thead>
<tr>
<th>Severe-to-profound hearing loss in Sweden</th>
<th>n=1280, n (%)</th>
<th>Participated/ Not participated/ Crude OR (95% CI)</th>
<th>p-value*</th>
<th>Adjusted OR (95% CI)</th>
<th>p-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not visited</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None/Some benefit</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group rehabilitation</td>
<td>16 (4.5)**</td>
<td>422 (13)</td>
<td>2.93 (1.80-4.78)**</td>
<td>0.000</td>
<td>2.78 (1.63-4.78)**</td>
</tr>
<tr>
<td>Audiologist</td>
<td>431 (12)</td>
<td>7 (9)</td>
<td>0.73 (0.36-1.50)</td>
<td>0.350</td>
<td>0.66 (0.30-1.45)</td>
</tr>
<tr>
<td>Technician</td>
<td>119 (11.5)</td>
<td>319 (12)</td>
<td>1.07 (0.88-1.31)</td>
<td>0.448</td>
<td>0.82 (0.63-1.07)</td>
</tr>
<tr>
<td>Welfare officer</td>
<td>78 (11)</td>
<td>360 (12)</td>
<td>1.10 (0.87-1.39)</td>
<td>0.396</td>
<td>0.79 (0.58-1.08)</td>
</tr>
<tr>
<td>Hearing rehabilitation educator</td>
<td>132 (9.5)**</td>
<td>306 (13.5)</td>
<td>1.39 (1.14-1.68)**</td>
<td>0.001</td>
<td>1.36 (1.06-1.75)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>8 (5.5)*</td>
<td>430 (12)</td>
<td>2.13 (1.08-4.21)*</td>
<td>0.020</td>
<td>1.48 (0.70-3.16)</td>
</tr>
<tr>
<td>Physician</td>
<td>89 (9)**</td>
<td>349 (13)</td>
<td>1.40 (1.12-1.74)**</td>
<td>0.002</td>
<td>1.20 (0.90-1.59)</td>
</tr>
<tr>
<td>Communication rehabilitation in group§</td>
<td>30 (7.5)**</td>
<td>408 (12.5)</td>
<td>1.68 (1.18-2.40)**</td>
<td>0.003</td>
<td>1.28 (0.84-1.95)</td>
</tr>
</tbody>
</table>

*The total number of answers 3661 (missing 623).
† p<.05; ** p<.01; *** p<.001
‡ Adjusted OR for these different areas for audiological rehabilitation.
§ e.g. sign language, sign support language, training for lips-reading, hearing tactics.
The findings revealed differences in patients’ health status (EQ5D) and significantly more negative impact of hearing loss on daily life (PIRS) for women than men (Table 8).

Table 8. The proportion of patients for different QoL outcomes, in patients with severe-to-profound hearing loss in Sweden with the proportions of male and female patients, crude odds ratios (OR) with 95% confidence intervals (CI) comparing gender differences (Paper II).

<table>
<thead>
<tr>
<th>Severe-to-profound hearing loss in Sweden</th>
<th>Total</th>
<th>Male n=2157</th>
<th>Female n=2129</th>
<th>Crude OR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>EQ5D&lt;0.7(b)</td>
<td>1033 (27.5)</td>
<td>447 (43.5)</td>
<td>586 (56.5)</td>
<td>0.68 (0.59-0.79)</td>
<td>0.000</td>
</tr>
<tr>
<td>PIRS≥70(c)</td>
<td>1440 (39.5)</td>
<td>674 (47)</td>
<td>766 (53)**</td>
<td>1.24 (1.09-1.42)**</td>
<td>0.001</td>
</tr>
</tbody>
</table>

* *p<.05; **p<.01; ***p<.001
There were some missing data. The total number of answers: \(b\) 3778, \(c\) 3623.

The total number of patients with bilateral hearing aids was only 56%, and significantly more women were fit with unilateral hearing aids (53.5%), and with unilateral CIs (58%), than men. A total of 12 patients had bilateral CIs, of whom 10 were women.

5.3 STUDY III

The results from Paper III showed that only 8.5% were rehabilitated with cochlear implants.

Only 16% of the 1076 patients in the study started a CI investigation despite meeting the criteria for CIs. Significantly more women (56.5%) were rehabilitated with CIs than men.

Patients with CIs were younger than patients without CIs.

The study investigated the reasons why patients were not rehabilitated with CIs: medical, hearing, patient, communication, or unknown reasons. The most common reason was hearing (33%), indicating that patients managed with hearing aids, and the second most common reason was unknown (25%) (Table 9). Hearing reasons and unknown reasons were most common in the oldest group (81-100 years old).

Patients rehabilitated with CIs also received significantly more extended audiological rehabilitation (97%) than patients without CIs (50%) (Table 10). The estimation scale for
QoL outcome regarding how hearing impairment affects daily life demonstrated no differences between the groups with or without CIs (Table 10).

Table 9. Reasons that 986 patients with severe-to-profound hearing loss were not rehabilitated with cochlear implants. Type of communication strategies in various reasons categories (Paper III).

<table>
<thead>
<tr>
<th>Age, Mean (±SD)</th>
<th>Medical</th>
<th>Hearing</th>
<th>Patient</th>
<th>Communication</th>
<th>CI invest start</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total =986</td>
<td>n=45</td>
<td>n=327</td>
<td>n=169</td>
<td>n=43</td>
<td>n=158</td>
<td>n=244</td>
</tr>
<tr>
<td>(4.5%)</td>
<td>(33%)</td>
<td>(17%)</td>
<td>(4.5%)</td>
<td>(16%)</td>
<td>(25%)</td>
<td></td>
</tr>
<tr>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female (n=480)</td>
<td>21 (5)</td>
<td>132 (31)</td>
<td>80 (18.5)</td>
<td>16 (3.5)</td>
<td>86 (20)</td>
<td>94 (22)</td>
</tr>
<tr>
<td>Male (n=596)</td>
<td>24 (4)</td>
<td>195 (35)</td>
<td>89 (16)</td>
<td>27 (5)</td>
<td>72 (13)</td>
<td>150 (27)</td>
</tr>
<tr>
<td>Age groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19-40 (n=75)</td>
<td>2 (3)</td>
<td>12 (18)</td>
<td>18 (27.5)</td>
<td>17 (26)</td>
<td>11 (16.5)</td>
<td>6 (9)</td>
</tr>
<tr>
<td>41-60 (n=171)</td>
<td>1 (0.5)</td>
<td>42 (28.5)</td>
<td>34 (23)</td>
<td>17 (11.5)</td>
<td>28 (19)</td>
<td>26 (17.5)</td>
</tr>
<tr>
<td>61-80 (n=487)</td>
<td>11 (2.5)</td>
<td>156 (35.5)</td>
<td>61 (14)</td>
<td>6 (1.5)</td>
<td>107 (24.5)</td>
<td>96 (22)</td>
</tr>
<tr>
<td>81-100 (n=342)</td>
<td>31 (9.5)</td>
<td>117 (35)</td>
<td>56 (16.5)</td>
<td>3 (1)</td>
<td>12 (3.5)</td>
<td>110 (34.5)</td>
</tr>
</tbody>
</table>

Table 10. The proportion of patients for extended audiological rehabilitation, QoL outcome (Estimation scale of hearing impairment impact on daily life) comparing patients with not cochlear implant (not CI) and with CI, crude odds ratios (OR) with 95% confidence intervals (Paper III).

<table>
<thead>
<tr>
<th>Total</th>
<th>Not CI</th>
<th>CI</th>
<th>Crude OR (95% confidence intervals)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=1076 (%)</td>
<td>n=986 (%)</td>
<td>n=90 (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extended audiological rehabilitation</td>
<td>578 (53.5)</td>
<td>491 (50)</td>
<td>87 (97)</td>
<td>29.23 (9.18-93.04)</td>
</tr>
<tr>
<td>Estimation scale ≥70%</td>
<td>336 (32.5)</td>
<td>305 (32.5)</td>
<td>31 (35)</td>
<td>1.12 (0.70-1.76)</td>
</tr>
</tbody>
</table>

*All p-values calculated with Chi-square test. *p<0.05, **p<0.01, ***p<0.001.
Total number of answers: b 979, c 881, d 878, e 866, f 891.
5.4 STUDY IV

In Paper IV, the demographic data on 76 patients with a mental fatigue score (MFS) >10.5 indicated no significant differences between genders. MFS levels were stratified into three scores: 10.5–15, 15.5–20, and 20.5 or more, and 67% of patients had the highest score area. Almost 90% of patients were working, although all of them were on temporary sick leave during undergoing rehabilitation at the clinic. Significant differences were found in terms of tinnitus, with 90% of patients with a THI ≥57 and an MFS scores ≥20.5 (Table 11).

Table 11. Demographic characteristics in patients with mental fatigue in three various score levels; 10.5-15, 15.5-20, ≥20.5 (Manuscript for Paper IV).

<table>
<thead>
<tr>
<th>Total</th>
<th>MFS score 10.5-15</th>
<th>MFS score 15.5-20</th>
<th>MFS score ≥20.5</th>
<th>p-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender; total</td>
<td>76</td>
<td>5 (6.5)</td>
<td>20 (26.5)</td>
<td>51 (67)*</td>
</tr>
<tr>
<td>Female</td>
<td>52 (69.5)</td>
<td>4 (7.2)</td>
<td>13 (24.2)</td>
<td>34 (65)</td>
</tr>
<tr>
<td>Male</td>
<td>23 (30.5)</td>
<td>1 (4.5)</td>
<td>7 (30.5)</td>
<td>15 (65)</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (±SD)</td>
<td>52.55 (6.06)</td>
<td>53.80 (4.76)</td>
<td>53.65 (6.18)</td>
<td>52.00 (6.15)</td>
</tr>
<tr>
<td>Range (years)</td>
<td>38-45</td>
<td>38-45</td>
<td>38-65</td>
<td>46-61</td>
</tr>
<tr>
<td>Civil status, Living alone*</td>
<td>18 (23.3)</td>
<td>2 (11)</td>
<td>4 (22)</td>
<td>12 (67)</td>
</tr>
<tr>
<td>Age groups (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-30</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>31-40</td>
<td>2 (4)</td>
<td>0 (0)</td>
<td>1 (22.2)</td>
<td>2 (61.5)</td>
</tr>
<tr>
<td>41-50</td>
<td>25 (33)</td>
<td>2 (8)</td>
<td>3 (12)</td>
<td>20 (80)</td>
</tr>
<tr>
<td>51-60</td>
<td>27 (34.2)</td>
<td>3 (8)</td>
<td>12 (22.2)</td>
<td>22 (68.5)</td>
</tr>
<tr>
<td>61-70</td>
<td>11 (14.5)</td>
<td>0 (0)</td>
<td>4 (35.5)</td>
<td>7 (63.5)</td>
</tr>
<tr>
<td>Degree of hearing loss, best ear*</td>
<td>0-25 dB HL</td>
<td>28 (37)</td>
<td>2 (7)</td>
<td>9 (31)</td>
</tr>
<tr>
<td>26-40 dB HL</td>
<td>12 (17)</td>
<td>1 (7.2)</td>
<td>1 (7.2)</td>
<td>11 (88)</td>
</tr>
<tr>
<td>41-70 dB HL</td>
<td>22 (29)</td>
<td>1 (4.5)</td>
<td>5 (22.2)</td>
<td>16 (73)</td>
</tr>
<tr>
<td>71-90 dB HL</td>
<td>7 (9)</td>
<td>1 (4.5)</td>
<td>2 (28.5)</td>
<td>4 (57)</td>
</tr>
<tr>
<td>&gt;90 dB HL</td>
<td>6 (8)</td>
<td>0 (0)</td>
<td>3 (50)</td>
<td>5 (79)</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>7 (9)</td>
<td>1 (4.5)</td>
<td>1 (14)</td>
<td>5 (72)</td>
</tr>
<tr>
<td>Working</td>
<td>68 (92.5)</td>
<td>4 (6)</td>
<td>19 (28)</td>
<td>45 (66)</td>
</tr>
<tr>
<td>Sick leave permanent</td>
<td>3 (1.5)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (100)</td>
</tr>
<tr>
<td>Sick leave*</td>
<td>44 (58)</td>
<td>2 (4.5)</td>
<td>14 (22)</td>
<td>28 (63.5)</td>
</tr>
<tr>
<td>Sick leave</td>
<td>73 (96)</td>
<td>4 (5.5)</td>
<td>20 (27.5)</td>
<td>49 (67)</td>
</tr>
<tr>
<td>Tinnitus; THI&lt;57</td>
<td>13 (17)</td>
<td>1 (7.5)</td>
<td>5 (38.5)</td>
<td>7 (54)</td>
</tr>
<tr>
<td>Tinnitus; THI ≥57</td>
<td>50 (65)</td>
<td>0 (0)</td>
<td>5 (10)</td>
<td>27 (50)</td>
</tr>
<tr>
<td>No tinnitus</td>
<td>33 (43.5)</td>
<td>4 (12)</td>
<td>12 (36.5)</td>
<td>17 (51.5)</td>
</tr>
<tr>
<td>Extended rehabilitative treatment</td>
<td>68 (89.5)</td>
<td>4 (6)</td>
<td>17 (25)</td>
<td>47 (69)</td>
</tr>
</tbody>
</table>

* All p-values calculated with Chi-square test.
* 1 (14.5%) had MFS g50
* No indication of civil status: 11 (14.5%) patients.
* HL=Hearing Level in decibel (dB); 0-25 dB HL=normal, 26-40 dB HL=mild, 41-70 dB HL=moderate, 71-90 dB HL=severe and 91-130 dB HL=profound hearing loss.
* On sick leave at the time of seeking health care at the clinic.
* On sick leave at the time as a patient in the clinic.
* THI=Tinnitus Handicap Inventory.

Most of the patients (n=28, 37%) had normal hearing, or moderate hearing loss (n=22, 29%) in the best ear, and most of the patients with normal hearing also had tinnitus with THI≥57 (n=17, 61%) (Table 11). Figure 4 demonstrates the proportion of tinnitus and hearing loss
degree in the best ear. Most patients with moderate hearing loss (41–70 dB HL) had no tinnitus (n=15, 68%), and most with normal hearing (0–25 dB HL) had THI ≥57 (n=15, 53.5%).

Figure 4. The proportion of tinnitus degree and degree of hearing loss, in the best ear (PTA4) (p=0.015).

The correlation analysis on the variables between MFS, PTA4 best ear, THI and HADS scores were performed (in reviewed Paper IV). The findings on the relationship between separate mental fatigue scores for moderate and severe MFS and hearing loss correlated significantly (Table 12). The results demonstrated a significant positive correlation, \( r=0.677^{**} \), between all MFS scores and tinnitus (Table 12, Figure 5). No significant correlation was detected between MFS and HADS-Anxiety or HADS-Depression. Figure 5 explains the correlation with MFS by PTA4 and THI. Only 2.7% of the total variance in MFS and for THI, a mild \( r=0.45 \), explained approximately 45.9% of the total variance in MFS (Table 12).
Figure 5. Correlation, $r^2$ Linear, between mental fatigue scale (MFS) scores and PTA4, and tinnitus score levels (In revised manuscript for Paper IV). MFS all scores by PTA4 best ear $r=0.027$, MFS all scores by THI score level $r=0.459$.

Table 12. Correlation analysis on all mental fatigue scores (MFS), and association with PTA4 levels best ear, THI scores, HADS-Anxiety and HADS-Depression score levels, and separately MFS score levels (10.5-15, 15.5-20, 20.5 or more) associated with PTA4 best ear, THI scores, HADS-Anxiety and HADS-Depression, with Pearson correlation coefficient ($r$) with 95% confidence intervals (CI). (In revised manuscript for Paper IV)

<table>
<thead>
<tr>
<th>Patients with mental fatigue score ≥10.5</th>
<th>n=76</th>
<th>PTA4* best ear</th>
<th>THI**</th>
<th>HADS-Anxiety</th>
<th>HADS-Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>MFS scores</td>
<td></td>
<td>n=76</td>
<td>n=76</td>
<td>n=22</td>
<td>n=22</td>
</tr>
<tr>
<td>Pearson $r$</td>
<td></td>
<td>0.165</td>
<td>0.677*</td>
<td>0.201</td>
<td>0.006</td>
</tr>
<tr>
<td>95% CI</td>
<td></td>
<td>(-0.091-0.389)</td>
<td>(0.564-0.790)</td>
<td>(-0.261-0.554)</td>
<td>(-0.508-0.523)</td>
</tr>
<tr>
<td>$p$-value</td>
<td></td>
<td>0.153</td>
<td>0.000**</td>
<td>0.371</td>
<td>0.980</td>
</tr>
<tr>
<td>MFS (10.5-15, 15.5-20, ≥20.5)*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pearson $r$</td>
<td></td>
<td>-0.279*</td>
<td>0.535**</td>
<td>0.378</td>
<td>0.134</td>
</tr>
<tr>
<td>95% CI</td>
<td></td>
<td>(0.071-0.419)</td>
<td>(0.326-0.763)</td>
<td>(-0.127-0.720)</td>
<td>(-0.310-0.643)</td>
</tr>
<tr>
<td>$p$-value</td>
<td></td>
<td>0.015*</td>
<td>0.000**</td>
<td>0.082</td>
<td>0.552</td>
</tr>
</tbody>
</table>

**Correlation is significant at the 0.01 level (2-tailed)
*Correlation is significant at the 0.05 level (2-tailed)
*PTA4 means the average pure-tone thresholds, i.e., at frequencies 0.5, 1, 2, 4 kHz in various degree of hearing loss in best ear: 0-25 dB HL, 26-40 dB HL, 41-70 dB HL, 71-90 dB HL and 91-130 dB HL.
**All tinnitus (THI) scores
$^c$Pearson correlation coefficient ($r$) with 90% confidence intervals.
*MFS mild (10.5-15): $r=-0.155$ (-0.296-0.009) $p=0.182$, MFS moderate (15.5-20): $r=-0.231$ (-0.396-0.032) $p=0.045$, and MFS severe (20.5 or more): $r=-0.288$ (-0.116-0.460) $p=0.009$. **
5.5 STUDY V

In Paper V, a total of 14 interviews were performed, with 7 women and 7 men between 47 and 81 years old, with dual sensory loss. For more demographic data, see Table 13. Causes for severe vision impairment were Usher Syndrome, keratoconus, retinitis pigmentosa, external damage, congenital blindness, glaucoma, rheumatism in childhood, incubator treatment at birth, and macular degeneration. Causes for severe hearing loss were noise trauma, childhood hearing loss, Meniere’s disease, and Usher Syndrome. All participated in undergoing audiological rehabilitation at the time of the interviews. All transcribed texts were analysed and categorized with content analysis into categories, sub-themes, and themes. The data resulted in interview areas (Figure 6) in 20 categories and six (6) sub-themes. Finally, two (2) main themes emerged: “Isolation” and “The ability to control one’s own daily life”.

Table 13. Demographic data. Gender, age, hearing and vision loss distribution of the interview patients (Manuscript for Paper V).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Women</th>
<th>Men</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41-50</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>51-60</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>61-70</td>
<td></td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>71-80</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>81-90</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>7</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td><strong>Mean age (year)</strong></td>
<td>70.8</td>
<td>69.4</td>
<td>70.1</td>
</tr>
<tr>
<td><strong>Hearing loss PTA4</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>best ear, mean (range)</td>
<td>69.4 (60-95)</td>
<td>75.1 (68-91)</td>
<td>72.2 (60-95)</td>
</tr>
<tr>
<td><strong>Vision loss, severe</strong></td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td><strong>Blindness, total</strong></td>
<td>43</td>
<td>44</td>
<td>8</td>
</tr>
</tbody>
</table>

1 Hearing loss PTA4 means the average of hearing level (HL) at 500, 1000, 2000 and 4000 Hz in the best ear.
2 Severe vision loss as, for example, caused by Usher II, retinitis pigmentosa, glaucoma, keratoconus, macular degeneration.
3 One participant is blind at one eye and severe vision loss in the other eye. One participant can only see dark and light.
4 One participant is blind at one eye and severe vision loss in the other eye.
Most participants did not perceive their disabilities with hearing and vision loss as a combined disability but rather as two separate afflictions. The combination entails limitations and challenges in everyday life, such as going out and orientating oneself in the surroundings, reading, shopping, and communicating with others. These limitations, in turn, isolate individuals. The study shows that companionship services is very important support for patients with dual sensory loss. The interviews showed that communities, during the last years, reduced the companion service hours for this patient group. This leads to a lack of independence in daily life and even more isolation. The participants demonstrated various strategies and creativity to gain control over their own lives and manage daily life situations.
6 DISCUSSION

The overall aim of the thesis was to investigate and present the quality and benefits of audiological rehabilitation for adult patients with severe-to-profound hearing loss, and two studies on patients with simultaneous severe vision impairment. Another purpose was to examine gender equality in Swedish hearing health care. Specific aims were to identify and characterize patients described above, patients rehabilitated with CI and patients with mental fatigue symptoms.

6.1 AUDIOLOGICAL REHABILITATION

The goals of audiological rehabilitation are to reduce the effects of hearing impairment and increase participation in daily social activities for patients with hearing loss (Boothroyd, 2007). The aural/audiological rehabilitation process should include a combination of management with technical aids and instructions, perception training, counselling to improve patients’ participation in daily life activities and QoL that have been affected by hearing loss (Boothroyd, 2007).

It is suggested that adult patients with sensory loss participate in multidisciplinary rehabilitation, especially with psychologists and social workers, to improve QoL, e.g., with group rehabilitation and communication training (Heine & Browning, 2002). Furthermore, hearing aids and audiological rehabilitation with counselling in groups increase the benefits of communication strategies (Chisolm et al., 2004).

In Paper II, group rehabilitation, communication with sign language/sign support language, and lip-reading training, or training with hearing tactics with group rehabilitation, were identified as having an important role in audiological rehabilitation. In particular, extended audiological rehabilitation with group rehabilitation and visiting a hearing rehabilitation educators/pedagogues had a significant impact on experiencing benefits from the rehabilitation received. However, only 32% of patients with dual sensory loss in Paper I and
40% of patients with severe-to-profound hearing loss in Paper II received extended audiological rehabilitation. The reasons for this may be that some of the patients have declined more efforts in extended audiological rehabilitation. Despite this, the profession must keep in mind, when treating patients who have sought care in a specialist clinic, the benefits of offering the opportunity to meet various professional competences or participate in group rehabilitation.

In contrast, 97% of patients with CI received extended audiological rehabilitation, compared to 50% of patients with no CIs (Paper III). This result was expected, as a CI investigation is an extensive process, including extended audiological rehabilitation, when evaluating whether CIs is an option. In Paper III the oldest patients, 81 to 100 years old, seemed to have the most ‘unknown reasons’ for not being rehabilitated with CIs. This is an important finding, although there can be medical reasons for not been rehabilitated with CI in this group. Hearing health care professionals should raise the issue, that the elderly are not ignored, and the reasons for not been rehabilitated with CIs should not be unknown. Hence, one indication for not having been rehabilitated with CIs, can be the lack of awareness both among professionals and patients, which other researchers have also demonstrated (De Raeye, 2016; Sorkin, 2013).

As stated above, patients with hearing disabilities need interventions with technical aids, hearing tactics, information and training, but also counselling to compensate hearing impairment and efforts to manage the social environment, stress, and fatigue (Stephens & Hétu, 1991). In Paper IV, almost all participants received extended audiological rehabilitation because these patients suffered from mental fatigue in combination with hearing loss and/or tinnitus with or without hearing loss. While undergoing audiological rehabilitation, almost all patients were on temporary sick leave. Mental fatigue affects daily life and the ability to work, sometimes for a long time, and can finally lead to permanent sick leave.
In Paper V, patients seemed to be satisfied with the audiological rehabilitation and support at the Low Vision Clinic. The Deafblind-team unit demonstrated an excellent level of competence and understanding of patients and their needs. The study identified the importance of continuity in health care and the positive routines that the Deafblind-team unit has with an annual appointment for every patient. This is in line with Grenness et al study in which a patient-centered audiological rehabilitation with individualized care and a focus on therapeutic relationships is suggested (Grenness et al., 2014).

6.2 DUAL SENSORY LOSS

Dual sensory loss with severe vision impairment in combination with severe-to-profound hearing loss, also called deafblindness, is a complex disability. Earlier studies emphasize that individuals with dual sensory loss are vulnerable and have several challenges affecting daily life activities, e.g., communication with other people, and information about their environment (Guthrie et al., 2018). This negatively affects their health related QoL, such as physical functioning and mental well-being (Chia et al., 2006).

In Paper I, patients with dual sensory loss were slightly younger in mean age compared to patients with severe-to-profound hearing loss. Dual sensory loss affects QoL due to communication difficulties, which in turn affects psychosocial functions (Heine & Browning, 2002). Our study identified significant negative effects for QoL outcomes, as identified by the EQ5D, PIRS and HADS scores for patients with dual sensory loss compared to patients with solely severe-to-profound hearing loss. Patients with dual sensory loss seemed to have a greater risk of experiencing more difficulties in health status and in terms of the impact of hearing loss on daily life, anxiety and depression than patients with solely severe-to-profound hearing loss. Among elderly population, similar results were found with an association with vision impairment and depressive syndrome, compared with the group that was not vision impaired, and with hearing loss and anxiety syndrome (Bernabei et al., 2011).
In Paper V, it was observed that several patients did not experience hearing and vision losses as a combination. One reason for that may be that these disabilities often progress independently. Most patients often named isolation and the inability to influence and control their own lives as their major setbacks of their disabilities. White canes turned out to have two sides: they were – a huge help in many situations but also a stigma and vulnerability because it made disability visible. It takes time to get used to the white cane; using it is often a positive experience for some patients, who named the white cane as their “loyal companion”. Another study showed that younger patients limited the use of the cane to avoid negative consequences in social life (Ehn et al., 2019). Support and limitations with the companion service were highlighted many times during interviews. Equal participation in social activities, an independent life and equal living conditions for persons with disabilities are important policies that the Swedish Agency for Participation (Myndigheten för delaktighet) advocates according to the UN Convention on the Rights of Persons with Disabilities (MFD, 2009). Full accessibility in society for all citizens is legislated, and the ambition is to break the isolation caused by functional ability (Socialstyrelsen, 2011d). Restrictions on this support service lead to even more isolation, and this needs to be examined. Many strategies were used by patients with dual sensory loss in daily life activities, which showed creativity and a willingness to be able to handle daily routines independently.

It is important to point out that the sum of two disabilities is not 1+1=2; it may be 1+1=4 or 1+1=5, particularly when one has a severe-to-profound hearing loss in combination with severe vision loss.

6.3 GENDER PERSPECTIVES IN AUDIOLOGICAL REHABILITATION

In Sweden, equal health care means that everyone must be offered care, that treatment should be delivered on equal terms irrespective of age, gender or disability, and that it can be achieved through a patient-focused approach (Socialstyrelsen, 2011a). The researchers of
Papers I-V emphasize that the gender perspective needs to be highlighted more in audiological rehabilitation.

In Paper I, there were almost an equal number of women and men in the dual sensory group and the control group with patients with severe-to-profound hearing loss only. Despite this, the findings indicated that more women than men received extended audiological rehabilitation in both the dual sensory group and in the control group. A possible explanation for the results with gender differences was that women, who generally have more severe hearing problems than men, tend to accept their hearing loss and they are more satisfied with hearing aids. Another explanation may be that women live longer and the need for rehabilitation increases with age.

Paper II found significantly more women than men to receive various audiological rehabilitation services. Women seemed to have more problems with aspects of their health and to experiences a significantly more negative impact of hearing loss on daily life than men. The causes for differences in help-seeking among genders were considered. Women may generally experience more severe hearing problems, more social life demands, or more easily seek care for their hearing problems than men. Interestingly, a systematic review of reasons that affect help-seeking found that self-perceived difficulties with hearing-limiting activities, were positively associated with all four outcomes, e.g., help-seeking, hearing aid uptake, use of hearing aids, and satisfaction (Knudsen et al., 2010). Self-reported hearing difficulties seemed to become an important factor in audiological rehabilitation according to Knudsen et al (2010). The same study highlighted the importance of having knowledge of one’s own hearing situation and being self-motivated. This requires great demands on hearing health care to have interventions capacity to help patients to be more aware and motivated to engage in hearing rehabilitation. One hypothesis for gender differences relating to significant more women received extended audiological rehabilitation than men, may be that hearing loss has still a negative stigma and, thus, may affect men more than women. A recent review
of 17 articles on stigma and hearing impairment showed that fear of stigma is an important factor in attitudes and negatively affects the audiological rehabilitation process and hearing aid use (Ruusuvuori et al., 2021). Hearing health care has an important role to communication and supporting to the general public more information about hearing loss, hearing aids and how to master the negative consequence of the social stigma associated with hearing loss.

There were more men than women in Paper III, of which significantly more women received CIs. Regarding reasons for not being rehabilitated with CIs, more men than women were found in the “unknown reason” group. More women than men had started CI-investigation when undergoing audiological rehabilitation. One possible reason may be that men are more satisfied with the hearing aids and other technical aids they received.

In Paper IV, the findings indicated a tendency for women to suffer more from mental fatigue. It was speculated that the reason may be that women are more willingly to seek care, similar to an earlier study (Paper II). The degree of hearing loss seemed to differ between gender groups. Women had more normal hearing and mild-to-moderate hearing loss and severe tinnitus than men in this pilot study. In both gender groups, almost an equal number of patients seemed to have mild fatigue level s(10.5-15), whereas in the severe mental fatigue group (≥20), there were more women than men. The opposite situation occurred in MFS scores of 15.5-20, in which there were more men than women.

Paper V study had an equal number of women and men. The mean age of women was slightly older, and women had better hearing (PTA4) in the best ear than men. This study did not compare other variables by gender.

6.4 MENTAL FATIGUE IN PATIENTS WITH HEARING LOSS AND/OR TINNITUS

Generally, circumstances with chronic health problems can cause fatigue and negatively effects QoL; this is also the case for fatigue related to hearing loss (Hornsby et al., 2016).
 Significant listening efforts due to hearing loss can cause negative effects on QoL and fatigue (Davis et al., 2021).

To the best of our knowledge, **Paper IV** is the first study focusing on mental fatigue in patients with hearing loss and/or tinnitus with or without hearing loss. More women than men seemed to suffer from mental fatigue. In Sweden, the annual statistics from the Swedish Social Insurance Agency (Försäkringskassan) (FK, 2021) shows that 59 percent women and 41 percent men were on sick leave with sickness compensation in 2020. Exhaustion and mental illness were most common in the younger age groups, 19-39 years, for both women and men. In age group 50 and more, more women seemed to suffer from mental illness than men (FK, 2021). Our study showed that four out of 10 participants had normal hearing in the best ear, and over half of the participants (56.5%) reported tinnitus problems, of whom almost 40% had severe tinnitus. Most of the individuals with mental fatigue had tinnitus. Notably, 67% of 76 patients had severe mental fatigue with a score of 20.5 or more. An important finding was that an extremely high MFS score of 30 or more was found in 11 patients. These 11 patients had evaluated their tinnitus with THI of 78-100. There is a need for more investigation to determine whether the chronic condition of hearing loss and/or tinnitus associated with a high degree of mental fatigue. Any relationship between the degree of hearing loss and fatigue were not found in an earlier study, and the connection with tinnitus was not investigated (Hornsby & Kipp, 2016). The present study demonstrated a strong correlation between all MFS scores and tinnitus. Apparently, severe tinnitus can be associated with severe mental fatigue. However, a significant correlation with separate MFS levels, moderate (15.5-20) and severe (≥20.5), and with hearing loss in the best ear was also found.

It is important to be able to use a validated instrument to measure fatigue in patients with hearing loss and tinnitus. Earlier studies utilized and evaluated the present MFS instrument in patients with mental fatigue after traumatic brain injury or stroke (Johansson & Rönnbäck, 2014). One of the present study purposes was to examine the usefulness of MFS as a
diagnostic instrument for patients who received audiological rehabilitation and were suffering from mental fatigue. Severe mental fatigue can affect the ability to work and may result in necessary sick leave – temporary or permanent - to manage daily life. The MFS in our hands in the clinic is used in the present clinic to provide crucial information in follow-up and in communication with the Social Insurance Agency (Försäkringskassan). Paper IV revealed the MFS questionnaire is a valuable tool to identify and examine causes of mental fatigue in the clinic, but more research is needed for guidelines and treatment in audiological rehabilitation.

For professionals at the clinic, it is important to have more knowledge about mental fatigue in combination with hearing loss and/or tinnitus. Audiological rehabilitation with medical, technical, social, and psychological interventions can provide great support for this patient group. Result in this study suggest that severe tinnitus can be associated with mental fatigue. More research is needed to understand more about the link between fatigue and hearing loss, but it is well known that at least hearing aids can reduce fatigue (Hornsby et al., 2016).

6.5 METHODOLOGICAL CONSIDERATIONS
This thesis, comprised of five studies that utilized both quantitative and qualitative methods, used a register-based data (Papers I-III), a clinical retrospective pilot study (Paper IV), and an interview study (Paper V). This aimed to obtain a broad holistic view of the situation of patients with severe-to-profound hearing impairment and patients with dual sensory loss. For national quality registers, broad consent is used, i.e., the patient must be informed in writing, the information to be provided is regulated in accordance with the European Data Protection Regulation GDPR, and all data are reported at the group level. Paper I-III used questionnaires from the quality register for severe-to-profound hearing loss. Paper IV used a self-reported MFS questionnaire. Paper I and II used a general questionnaire and complementary health questionnaires, including EQ5D and PIRS. HADS was added in Paper I. A new baseline questionnaire was used in Paper III. In the baseline included
questions about reasons for not been rehabilitated with CI, tinnitus, and dizziness. The earlier PIRS was remade to the estimation scale in the baseline questionnaire. **Paper IV** aimed to investigate a new approach with mental fatigue and decided to be carry out a pilot study. This study used the MFS questionnaire, HADS, THI, and medical records. The use of a qualitative approach, in **Paper V**, was considered the best to answer the research questions. A semi-structured interview guide was used. A challenge in many interview studies is the number of participants, which in this study may be considered relatively low. For sampling validity, the present study managed to obtain a broad age distribution and the same number of women and men to represent the population (Krippendorff, 2013). In qualitative research, the number of participants may be determined when the research question is answered and when thematic saturation is achieved, i.e., little new information emerges (Weller et al., 2018). **Paper V** used the content analysis when creating data to codes, categories, and themes. Thematic saturation were considered when analysing the data. A study with 25 interviews found most new codes and code definitions in interviews 1 to 6, and code and thematic saturation were reached after nine interviews (Hennink et al., 2017). However, the same study recommended 16–24 interviews to reach meaning saturation.

The analysis methods in **Papers I-IV** used categorized data, in some cases dichotomized, and followed the questionnaires, with the commonly used cut-off score of 8 for HADS (Bjelland et al., 2002; Zigmond & Snaith, 1983), 10.5 for MFS (Johansson & Rönnbäck, 2014), 70 for the estimation scale (earlier PIRS) (Carlsson et al., 2011; ORL, 2020), and 57 for THI (McCombe et al., 2001). In **Paper II**, the decision to perform analysis on patients with “None/Some” benefits of audiological rehabilitation was based on the fact that we wanted to focus on that group to determine type of rehabilitation they received and why they experienced no or only minor benefits of the rehabilitation. In **Paper V**, interviews were analysed and categorized using content analysis to find meaningful structures. Audio-recorded interviews and verbatim transcription controlled all transcribed texts several times.
Four of five researchers worked with condensate meaning units, analysed categories and finally to themes increase trustworthiness and credibility in the study.

6.6 STRENGTHS AND LIMITATIONS

In general, this thesis with five studies, is considered to have a broad range of three quantitative studies with registered data, one pilot study on medical records, and a qualitative interview study. A strength of the research is the large samples in the register-based studies in Papers I-III, with good statistical power (Thygesen & Ersbøll, 2014). Limitations may be that the data were pre-collected by other persons, and some information may be unavailable. The pilot study on mental fatigue, Paper IV, is timely and growing in popularity and needs more research. The present retrospective study investigates a new intervention for mental fatigue in patients visiting audiological rehabilitation. An interview study, Paper V, raises awareness of the patient group's experiences in a deeper way than a qualitative study had revealed. Patients with deafblindness, studied in Paper V, are a relatively small population in Sweden. Thus, the number of patients was acceptable for an interview study and provided much information and answers to research questions.
CONCLUSIONS

The conclusions of this thesis are as follows:

Patients with dual sensory loss had a higher risk for a negative impact on health-related activities, e.g., mobility and self-care, levels of anxiety and depression, than patients with solely severe-to-profound hearing loss.

Notably, only 40.5% of patients with severe-to-profound hearing loss received extended audiological rehabilitation. Hearing loss had a significantly more negative effect on women’s daily life than that on men’s. Women also received more extended audiological rehabilitation than men.

In conclusion, only 8.5% in the quality register were rehabilitated with CIs despite fulfilling the criteria for CI. Various reasons for not being rehabilitated with CIs were medical, hearing, patient, communication, and unknown reasons. The most common reason was hearing and unknown reasons. Twenty-five percent had unknown reason, and elderly individuals (81–100 years old) seemed to have more unknown risk reasons.

The study introduces a new validated self-reported Mental Fatigue Scale (MFS) for patients with hearing loss and/or tinnitus. Severe mental fatigue is common in patients with chronic conditions in which hearing loss and/or especially tinnitus occur.

Dual sensory loss, with severe hearing and vision impairment, is isolating and affects daily life. The participants also highlighted the importance of having control over their own lives. Community-organized companion services need further examination to increase individuals' independence.

In summary, these findings add new knowledge, and rationales for extended audiological rehabilitation and the need for the skills and competences of multiple specialists in hearing health care for patients with severe-to-profound hearing loss.
8 POINTS OF PERSPECTIVES

8.1 CLINICAL IMPLICATIONS
The main clinical implication is that patients with severe-to-profound hearing loss and with dual sensory loss need extended audiological rehabilitation.

Professionals who meet patients with severe-to-profound hearing loss need to be aware of the criteria for CIs and inform patients more about the option.

A self-reported instrument (MFS) was implemented to measure mental fatigue in patients with hearing loss and tinnitus is needed for better identification of this patient group.

Patients with dual sensory loss are a vulnerable group and need more extended audiological rehabilitation. There is a need for greater understanding in society of the combination of vision and hearing impairment.

8.2 FUTURE PERSPECTIVE
Various future directions might be of interest both in qualitative and quantitative approaches.

More investigations using in-depth interviews to explore the consequences of dual sensory loss will generate even more transparency about the effects of hearing loss in their daily lives.

There is a need to develop evidence-based guidelines for audiological interventions and treatments for patients suffering from mental fatigue in combination with hearing loss and tinnitus with or without hearing loss.
9 CONFERENCE CONTRIBUTIONS

The author has presented research at both national and international conferences.

2016  International Clinical Linguistics and Phonetics Association (ICPLA), Halifax Canada
2016  World Congress of Audiology (WCA2016), Vancouver, Canada
2017  Audiologisk dag, Svenska Audiologiska Sällskapet (SAS), Västerås, Sweden
2018  TeMA Hörsel, Örebro, Sweden
2018  World Congress of Audiology (WCA2018), Cape Town, South Africa
2019  Cochlear Nordic Symposium, Malmö, Sweden
2019  Rikskonferensen för Svenska Audionomföreningen (SvAf), Tylösand, Sweden
2019  Swedish Institute for Disability Research Linnaeus Centre HEAD Graduate School, Linköping, Sweden
2019  Cognitive hearing science for communication (CHScom2019), Linköping, Sweden
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