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Internet Interventions for Hearing Loss

Examining rehabilitation, self-report measures and internet use for hearing-aid users

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*Technology is nothing.
What's important is that you have a faith in people,
that they're basically good and smart,
and if you give them tools,
they'll do wonderful things with them.*

Steve Jobs

To Per, Oscar, Philip & Clara

ABSTRACT

In the future, the rehabilitation of adults with hearing loss is likely to involve modern information technology. It is therefore important to determine whether and to what extent adults with hearing losses use the internet. When evaluating hearing rehabilitation, it is reasonable to use self-report questionnaires as outcome measures. The questionnaires used in audiological research are developed and validated for paper-and-pencil administration. Standardized questionnaires used in the audiological context should also be evaluated in an online administration format. Using the internet in the audiological rehabilitation process might be a cost-effective way to include additional rehabilitation components by guiding hearing-aid users on topics such as communication strategies, hearing tactics and how to handle hearing aids. The development of online rehabilitation programs might foster behavioral changes that will positively affect hearing-aid users.

Four studies were conducted with a total of 338 participating hearing-aid users. In the first study, the participants' amount of internet use was investigated. In the second study, the administration format (online vs. paper-and-pencil) of four standardized questionnaires used in hearing research and clinics were evaluated. Finally, two randomized controlled trials were performed to evaluate the efficacy of an online rehabilitation program that included professional guidance by an audiologist. The program lasted over five weeks and was designed for adult, experienced hearing-aid users. The effects of the online programs were compared with the effects of a control group. In the first randomized controlled trial, the participants of the control group participated in an online discussion forum without any professional contact (Study III). In the second randomized controlled trial, the control group participants were informed that the rehabilitation program was full and they were transferred to a waiting list pending treatment (Study IV).

The results in the first study showed that 60% of the participating hearing-aid users used computers and the internet. The internet use level was at least at the same level for people with hearing loss as for the general age-matched population in Sweden. In the second study a significant main effect of questionnaire format was found for one questionnaire, which evaluated the participants' activity limitations and participation restrictions; the participants had higher scores on the online format than on the paper format. Other than that, no interaction effects for format were found for the other three questionnaires. In the first randomized controlled trial, after the five-week online rehabilitation program, both groups of participants showed significant improvements and the effects were maintained in domains of activity limitation and participation restriction at the six-month follow-up. Moreover, effects in psychosocial domains were found. In the second randomized

controlled trial, after the five-week online rehabilitation, the participants showed significant improvements in the domains of activity limitation and participation restriction. The effects were maintained and improved at the three-month follow-up. Additionally, significant improvements in the domain of psychosocial well-being were found at the three-month follow-up.

It can be concluded that the level of computer and internet use is at least the same for people with hearing loss as for the general age-matched population in Sweden. Furthermore, for three of the four included questionnaires, the participants' scores remained the same across formats. It is recommended that the administration format remain consistent across assessment points. Finally, results from the studies provide preliminary evidence that the internet can be used to deliver education and rehabilitation to experienced hearing-aid users who report residual hearing problems and that their problems are reduced by the intervention; however, the content and format of the online rehabilitation program requires further investigation.

LIST OF PUBLICATIONS

This thesis is based on the studies reported in the following papers, which will be referred to in the text by their Roman numerals.

- I. Thorén ES, Öberg M, Wänström G, Andersson G, Lunner T. (2013). Internet access and use in adults with hearing impairment. *J Med Internet Res*, 9, 15, 5:e91.
- II. Thorén ES, Andersson G, Lunner T. (2012). The use of research questionnaires with hearing impaired adults: Online vs. paper-and-pencil administration. *BMC Ear Nose Throat Disord*, 12, 1.
- III. Thorén E, Svensson M, Törnqvist A, Andersson G, Carlbring C, Lunner T. (2011). Rehabilitative Online Education versus Internet Discussion Group for Hearing Aid Users: A Randomized Controlled Trial. *J Am Acad Audiol*, 22, 274–285.
- IV. Thorén ES, Öberg M, Wänström G, Andersson G, Lunner T. A randomized controlled trial evaluating the effects of online rehabilitative intervention for adult hearing-aid users. *Submitted manuscript*

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LIST OF ABBREVIATIONS

ACE	Active Communication Education
ANCOVA	Analysis of Covariance
ANOVA	Analysis of Variance
CONSORT	CONsolidated Standards of Reporting Trials
dB HL	Decibel Hearing Level
ENT	Ear, Nose and Throat (-physician)
HADS	The Hospital Anxiety and Depression Scale
HADS-A	Hospital Anxiety and Depression Scale, Anxiety subscale
HADS-D	Hospital Anxiety and Depression Scale, Depression subscale
HHIE	Hearing Handicap Inventory for the Elderly
HHIE-E	Hearing Handicap Inventory for the Elderly, Emotional Consequences subscale
HHIE-S	Hearing Handicap Inventory for the Elderly, Social Consequences subscale
ICF	International Classification of Functioning
ITT	Intention To Treat
IOI-HA	The International Outcome Inventory for Hearing Aids
LACE	Listening and Communication Enhancement
LOCF	Last Observation Carried Forward
PTA	Pure Tone Average; Average of the pure-tone hearing threshold levels at 500, 1000, 2000 and 4000 Hz
RCT	Randomized Controlled Trial
SADL	Satisfaction with Amplification in Daily Life
SADL-SC	Satisfaction with Amplification in Daily Life, Service and Cost subscale
T0	Data collected before the intervention
T1	Data collected immediately after the intervention was finished
T2	Data collected at follow-up (three months or six months)
WHO	World Health Organization
YLD	Years Lost Due to Disability

INTRODUCTION

The latest figures from the World Health Organization (WHO) show that five percent of the world's population has some kind of hearing loss; therefore, hearing loss is one of the most common disabilities worldwide and one of the most common disabilities that affect the senses (Stevens et al., 2013; WHO, 2001). Hearing disability is correlated with increased age (Davis, 1989); among people over the age of 65 years, nearly one-third are affected by impaired hearing (WHO, 2001). The WHO's list of calculated Years Lost Due to Disability (YLD) worldwide ranks hearing loss as the second leading cause of years lost, after depression and before alcohol use.

The risk of developing a hearing loss increases with age. It is a disability that affects the majority of the world's population, either because of a first-hand hearing loss or the hearing loss of a significant other. In addition to the direct and obvious effects of a hearing loss, such as difficulties with hearing speech, music and other (weaker) sounds, there are also a number of indirect psychological and psychosocial effects. Limited access to services and exclusion from communication can have a significant impact on everyday activities and quality of life, causing feelings of loneliness, isolation and frustration, particularly among older people with hearing loss (Dalton et al., 2003). For people of working age, the effects can manifest as trouble managing certain job situations and negative influences on relationships with spouses when misunderstandings and inactivity in conversations increase (Danermark and Gellerstedt, 2004; Héту et al., 1993; Nachtegaal et al., 2012).

The most common and accepted treatment for hearing loss is audiological or aural rehabilitation, including hearing aids (Chisolm et al., 2007). The steps that should constitute audiological rehabilitation are subject to ongoing discussion (Laplanche-Lévesque et al., 2010), but hearing aids are a central aspect that is accepted by both users and professionals. Today's advanced hearing aids help people with hearing loss in many difficult communication situations, but it is also well known that even modern hearing aids cannot provide complete rehabilitation (Kochkin, 2000).

Although objective measurements of the benefits of hearing-aid use can be shown after a hearing-aid fitting, there is no guarantee that a person with hearing loss will use the hearing aids when the rehabilitation is finished (Arlinger, 2003; Hickson et al., 1999; Hickson and Worrall, 2003; Kramer et al., 2005). A hearing-aid user's satisfaction depends largely on his or her emotional state and personal experiences. Research has shown that subjective measurements of satisfaction are an important success criterion for hearing-aid users (Andersson, 1995). Furthermore, studies have shown that hearing-aid users tend to

use their hearing aids more and become more satisfied with them when they participate in a more thorough rehabilitation program that includes courses on communication strategies and how to use hearing aids (Hickson and Worrall, 2003; Kramer et al., 2005). Many hearing-aid users have additional and persistent hearing problems after they complete a hearing aid fitting, but have difficulty knowing which corrective actions to take (Popelka et al., 1998; Southall et al., 2006). It has been shown that when hearing-aid users use their hearing aids more regularly, their attitude towards hearing aids becomes more positive (Eriksson-Mangold et al., 1990). This indicates that for many adults with hearing losses, interventionists can do much more than just finding the best hearing aid for a given client.

Currently, only a select few patients have the opportunity to participate in a thorough rehabilitation program when receiving hearing aids. Most often, these programs are tailored for special groups of adults with hearing losses, such as people with severe hearing loss or those who have a specific work situation (Montano, 2009). This means that most adults with hearing losses are not offered additional rehabilitation after they are fitted with hearing aids (Öberg et al., 2009).

Various alterations could be made to the audiological rehabilitation to improve the process and create conditions that help the patient become a satisfied hearing-aid user. Such alterations might include hearing tactics, information about hearing aids and the physiology of the hearing system and how to develop communication skills (Gagné and Jennings, 2008). The inclusion of psychosocial factors in the rehabilitation of adults with hearing loss has been examined in terms of correlations between hearing-aid usage and user satisfaction (Öberg et al., 2007). The results are in line with a hypothesis that a focused and structured rehabilitation program is beneficial for hearing-aid users.

When considering the possibility of offering further rehabilitation to a greater number of hearing-aid users, the internet could prove to be a useful medium. The internet can be seen as a potentially useful recruitment and counseling tool for rehabilitation; via the internet, information can be provided and advice can be given on a continuous basis with significantly shorter communication paths between patients and professionals in terms of both time and geography (Carlbring and Andersson, 2006). Technology such as the internet may present new, creative and cost-effective ways to recruit and rehabilitate people with hearing loss (Laplante-Lévesque et al., 2006). The internet is still seen as a medium that is more widely used by younger than older people (Henshaw et al., 2012; Kiel, 2005). A new generation of potential hearing-aid users is emerging who perceive the internet as a useful tool in their everyday life and not as an obstacle. It is highly important to investigate how much people with hearing loss actually use the internet and determine what kinds of online rehabilitative solutions are possible to introduce.

BACKGROUND

Audiological Rehabilitation

In 2001, the WHO redefined the International Classification of Functioning (ICF; WHO, 2001) system with the aim of illustrating a conceptual model of rehabilitation across health conditions and countries. The revised classification system included an important part that distinguished it from the earlier version (WHO, 1980); this part stated that a health condition may be caused by complex interactions of functioning at levels of the body, the person and the society. To describe the factors of *person* and *society*, the ICF terminology of activity/activity limitation and participation/participation restriction was used.

The translation of the WHO model into the field of audiology, together with some approaches from earlier work (Stephens and Héту, 1991), has resulted in the following goal for audiological rehabilitation: *“to restore or optimize participation in activities considered limitative by persons who have a hearing impairment or by other individuals who partake in activities that include persons with a hearing impairment”* (Gagné, 2000, pp. 65).

One outcome of audiological rehabilitation is to achieve behavioral change (McKenna, 1987; Prochaska et al., 2008; Saunders et al., 2013) and focus on where and how the person with hearing loss can use his or her skills to reach a higher level of functioning instead of focusing only on technically reducing the hearing loss (McKenna, 1987). The notion that behavioral change should be implicit in the rehabilitation plan was also described in the Audiological Rehabilitation Management Model by Goldstein and Stephens (1981).

To achieve behavioral change, an intervention may involve personal adjustments, including the person’s behavioral, emotional, cognitive, physical and interpersonal reactions to the hearing loss (Schum, 1994) and dimensions of empowerment (Barak and Sadosky, 2008; Erdman et al., 1994; Kricos, 2006). Empowerment is often described as a complex process of personal change (Aujoulat et al., 2007; Poost-Foroosh et al., 2011). Although no clear definitions are available, the term is generally associated with coping, interaction, personal effectiveness, competence and self-confidence (Gibson, 1991). When used in audiology, the concept of empowerment also includes descriptions of inter- and intrapersonal perspectives (Aujoulat et al., 2007; Poost-Foroosh et al., 2011). Readiness to undergo rehabilitation and use hearing aids has been described in terms associated with an intrapersonal view of empowerment and client-centered interaction is associated with an interpersonal view of empowerment (Poost-Foroosh et al., 2011). These findings are interesting when it comes to developing future audiological rehabilitation programs.

It is widely accepted that rehabilitation is a process that occurs over a long time (Erdman, 1993; Schum, 1994). The audiological rehabilitation process can be explained as a model of active processes in which the goal is audiological enablement, as described by Stephens and Kramer (2010). The last elements in their model are *short-term remediation* and *on-going remediation*. In addition to adequate hearing aids, the model recommends that rehabilitation should include communication partners and the authors concluded that it may take years to achieve *optimal enablement*. In a model of audiological rehabilitation described by Boothroyd (2007, pp. 64), the overall goal is to “*reduce or eliminate these various deficits and, as far as possible, restore the individual to his or her preloss state*”. Audiological rehabilitation can be viewed as a prolonged process of accepting the hearing loss, adapt to living with the hearing loss as well as adapt to the use of hearing aids (Jerram and Purdy, 2001; Meyer and Hickson, 2012). Furthermore, Boothroyd described that a holistic approach to audiological rehabilitation should include a mixture of the following four components: sensory management, instruction (e.g., on the use of hearing devices), perceptual training (focusing on everyday communication) and counseling (focusing on quality of life). Boothroyd concluded that it is a challenge to achieve the goal of a holistic audiological rehabilitation without increased costs and suggests that some aspects of rehabilitation can occur via computer-based programs and in group settings.

A connection between hearing loss and psychological factors has been identified, for example, in the form of a correlation between hearing loss and depressive symptoms, particularly among older adults (Erdman, 2009). Furthermore, it is suggested that “*behavioral treatments could help elderly people solve problems associated with their hearing loss*” (Andersson, 1995, pp. 31) and that rehabilitation must focus on emotional aspects of the hearing difficulties (Danermark, 1998). Other researchers state that the inclusion of additional audiological rehabilitation programs should produce differences in quality of life (Abrams et al., 2002). Further, a review by Arlinger (2003) concluded that uncorrected hearing loss has not only negative consequences in the obvious terms of auditory impairment but also in psychological domains, such as increased symptoms of depression.

Elements included in Audiological Rehabilitation

The elements included in an audiological rehabilitation program can vary and no consensus has been established. However, for many people with hearing loss, audiological rehabilitation focuses on hearing aids (e.g., Hickson et al., 2006), although not all people view hearing aids as the key solution to their hearing problem (Kochkin, 2009). Many hearing-aid users have further and persistent hearing problems after rehabilitation, including difficulties knowing what actions to take to address problems (Popelka et al., 1998; Southall et al., 2006). Hickson and colleagues have shown that people either stop using their hearing aids or continue searching for more help and guidance (Hickson et al.,

2007). For many hearing-aid users, it is essential to obtain further and extended rehabilitation to become satisfied with their hearing aids and overcome participation restrictions and activity limitations (Northern and Beyer, 1999; Sanders, 1971).

Many models and definitions of audiological rehabilitation share a common focus on systematic training, individualized programming and the relevance of personal and subjective outcomes (Gagné, 1998; Kricos, 2006; Montano, 2009) and the continuous process of accepting the hearing loss and not just using hearing aids (Meyer and Hickson, 2012). A frequent key word is problem-solving, which is described as an *“exercise aimed at the reduction of disability and the avoidance of handicap”* (Stephens and Héту, 1991, pp. 190) and not just a simple cure (Gagné et al., 1995). Working with problem-solving methods and strategies to resolve hearing-loss related problems can include working on strategies related to the patient, to significant others and to the physical environment (Gagné and Jennings, 2008).

To focus on factors other than just hearing aids, some researchers have achieved promising results by including group training and focusing on reducing activity limitations and participation restrictions (Abrams et al., 1992; Hawkins, 2005). Other researchers focused on domains such as psychosocial functions (Kricos and Holmes, 1996) and found that including these domains in the rehabilitation produced larger effects than hearing aids alone did (Beynon et al., 1997).

Parts of the rehabilitation, such as finding correct devices, are often delivered on an individual basis, where the focus is the person's problems and needs. Other parts of the rehabilitation may take place in a group setting, which can facilitate important interaction and learning between the group members (Stephens and Kramer, 2009). Preminger and Yoo (2010) presented the results of a study in which they investigated the effects of group-based aural rehabilitation and concluded that it is important that the rehabilitation program includes a mixture of information, training and psychosocial exercises to produce significant effects on the participants' activity limitations and participation restrictions.

The Active Communication Education (ACE) program was developed with a focus on older people with hearing losses and hearing difficulties (Hickson et al., 1999; Hickson and Worall, 2003). The goal of the program is to reduce the participants' communication difficulties and enhance their quality of life. The ACE program focuses on problematic everyday communication situations. In the program, the group meets for two hours per week over a five week period. At each meeting, the group works with a new module. The module consists of problematic communication situations, such as listening to television, going to a restaurant and conversing at a dinner table. The outcome of the program

showed positive results in domains such as quality of life (Hickson et al., 2006). The ACE program has been translated into Swedish and successfully evaluated in groups of elderly hearing-aid users (Öberg et al., in press).

Kramer and colleagues have developed and evaluated a video-based home-training program (Kramer et al., 2005). The program focuses on educating hearing-aid users and significant others and the program consist of videos of everyday situations that are familiar to most people with hearing losses. The aim with the videos is to show how a given everyday situation is perceived when you have a hearing loss and how communication is affected. The program produced positive results, i.e., improved interaction with significant others and improvements in domains such as quality of life and hearing aid satisfaction (Kramer et al., 2005). The study highlighted the importance of including interventions in addition to hearing aid fitting. Another home-based education program is called Listening and Communication Enhancement (LACE). LACE focuses on training the subjects' cognitive skills, communication strategies and understanding of rapid speech in a home-based training program with interactive and adaptive tasks (Henderson Sabes and Sweetow, 2007; Sweetow and Henderson Sabes, 2006). The results indicate that nearly 80% of the subjects improved to some degree on both subjective and objective outcome measures. The results also show that the subjects were highly motivated because the program was home-based and time-efficient (Olson et al., 2013).

Outcome measures for audiological rehabilitation

The evaluation of hearing aid use often includes some kind of objective measurement, such as speech recognition tests or real ear measurements. The efficacy of hearing aids can also be measured according to the user's own perceptions of the results of rehabilitation, including hearing aid fitting, via some kind of self-report to evaluate the process and the result (Noble, 2013). Satisfaction with hearing aids, for example, can be evaluated using the standardized questionnaire Satisfaction with Amplification in Daily Life (SADL, Cox and Alexander, 1999; Cox and Alexander, 2001). A questionnaire that is frequently used to evaluate rehabilitation, including hearing aids or additional rehabilitation programs, is the Hearing Handicap Inventory for the Elderly (HHIE, Ventry and Weinstein, 1982; Weinstein et al., 1986; Weinstein and Ventry, 1983; Öberg et al., 2007). This questionnaire was designed to measure the different dimensions of hearing loss, including physical and social parameters (Cox, 2003). The outcome of these self-reports are aligned with ICF terminology (WHO, 2001) and the domains of activity limitation and participation restriction. A questionnaire that is widely used in studies worldwide and that has been translated into many languages (Cox et al., 2002) is the International Outcome Inventory of Hearing Aids (IOI-HA, Brännström and Wennerström, 2010; Cox and Alexander, 2002; Cox et al., 2000; Cox et al., 2002). The questionnaire includes questions related to the most

important domains (Humes et al., 2001): hearing aid use, hearing aid benefits, residual activity limitation, satisfaction, residual participation restriction, impact on others and quality of life. Domains other than hearing ability, such as psychosocial elements, have turned out to be important in audiological rehabilitation (Preminger, 2007). Researchers have shown negative correlations between uncorrected hearing loss and symptoms of depression (Nachtegaal et al., 2009; Pronk et al., 2013). In some studies pertaining to hearing-related evaluations, the Hospital Anxiety and Depression Scale (HADS) has been used (Kaldo-Sandström et al., 2004; Öberg et al., 2008).

The abovementioned questionnaires are considered reliable and internally valid in the Swedish language (Lisspers et al., 1997; Öberg et al., 2007; Öberg et al., 2009), but none but the HADS has been validated for internet use (Andersson et al., 2003). The American Psychological Association has suggested that norms and criteria for online questionnaires should be obtained before they are used as a replacement for the paper-and pencil questionnaires (American Psychological Association, 1986; Buchanan, 2002).

Internet

In today's society, almost everybody is familiar with using the internet. In the future, internet and computer use will be an even more frequent and natural part of everyday life. For example, people with hearing loss search for information about hearing and hearing loss after receiving a hearing loss diagnosis from an ENT-physician (Laplanche-Lévesque et al., 2012). Not everything published on the internet is valid and relevant (Mayer et al., 2006); consequently, the information seeker may read misleading information about what actually is wrong with their hearing. The audiological community may to a greater extent offer scientifically proven information and simplify the possibilities for contact with audiological professionals via the internet. The internet might be a useful medium for reaching out to people with residual hearing problems in a cost-effectively way to help them in their process of accepting their hearing situation and living their lives as they wish with their hearing abilities.

With the internet, it is possible to inform and guide people with hearing loss in communication strategies, hearing tactics and how to handle their hearing aids without the inconvenience of visiting the hospital. Several studies have shown the success of screening the subjects' hearing via the telephone and the internet (Smits et al., 2006a; Smits et al., 2006b; Smits and Houtgast, 2005). The results indicate that subgroups, particularly younger people, are better reached by the internet rather than the telephone. The screening test situations are relatively reliable and representative of real-life conditions because they present conditions that approximate everyday life situations in which many people with hearing loss have communication difficulties (Thodi et al., 2013).

The internet is well suited for research purposes because rating scales and questionnaires are easily administered via internet. Studies in adjacent research fields, such as tinnitus, anxiety and panic disorders, have shown promising results when using the internet to guide and treat patients (Andersson et al., 2002; Andersson et al., 2005; Andersson et al., 2013; Kaldo-Sandström et al., 2004). There are pros and cons of using the internet in rehabilitation situations directed toward people with hearing loss; for example, the effects of the rehabilitation may be harder to detect via the internet because the participants only interact with the audiologist online and never have personal contact. In contrast, rehabilitation via the internet might make it possible to better meet patients' individual needs and include elements in the rehabilitation process that would otherwise be overlooked, such as hearing tactics and information about communication strategies. Consequently, aspects of the audiological rehabilitation that often are overlooked and not prioritized, such as psychosocial elements and contact with peers, could be included (Stephens and Kramer, 2010).

Under the best of circumstances, with unlimited time and money, it might be easy to create an audiological intervention to meet the needs of hearing-aid users who have residual hearing problems. To overcome the problems of limited resources, the alternative is to develop a cost-effective way to provide the necessary rehabilitation.

AIMS

The general aim of this thesis was to study the possibilities of including online and interactive tools in the rehabilitation process of adult hearing-aid users. The studies presented in Papers I and II can be seen as studies of the early phase of screening and assessment, whereas Papers III and IV address rehabilitation via the internet.

In Paper I, the prevalence of internet, computer and e-mail use was evaluated in a group of adults with hearing loss who were experienced hearing-aid users. The study was designed to determine whether hearing-aid users use modern technology like the internet and computers differently than the general population of Sweden does. Furthermore, the aim of the study presented in Paper I was to determine whether it is possible to offer some elements of audiological rehabilitation and professional contact via the internet in the near future.

Furthermore, in Paper II, online and paper-and-pencil administration of questionnaires measuring hearing-related issues were compared. Research on hearing, hearing loss and audiological rehabilitation often use self-report outcome measures (e.g., Noble, 2013). A majority of the questionnaires used in audiological research have not previously been validated in an online format and psychometric characteristics are only available for the paper-and-pencil format. In the context of online rehabilitation, it is important to use outcome measures in an online administration format. The aim of Study II was to validate questionnaires that are often used in hearing research for internet use.

In the studies presented in Papers III and IV the aim was to determine the effects of two slightly different online, interactive, educational and rehabilitative programs. The studies were designed to evaluate whether it is possible to use such online programs in the rehabilitation process of hearing-aid users. Furthermore, the studies were designed to compare the online rehabilitation users with control groups either taking part in an attention-based control program or who were on a waiting list pending treatment.

ETHICAL CONSIDERATION

The medical ethics committee of Linköping, Sweden, approved the protocols for each study (M190-08, T39-09).

THE EMPIRICAL STUDIES

General Methods

The outcome measures used in the studies are primarily self-reports (subjective assessment by questionnaires; Table 1). In Study I, a questionnaire developed for the specific research project about internet, computer and e-mail use was applied. In Studies II-IV, the following questionnaires were used: HHIE, IOI-HA, HADS and SADL. In Study II, the same questionnaires were used twice, but the participants filled them out in different formats (online vs. paper). In Studies III and IV, the questionnaires were used three times: before the study, directly after the study and at a follow up at three or six months after the study was finished.

Study III and IV were designed as Randomized Controlled Trials (RCT). This design was chosen to analyze the relationship between treatment and outcomes with an optimal procedure and to minimize the possibility that a relationship between the intervention and outcome could be explained by a third factor (Sibbald and Roland, 1998). The RCT's design largely followed the CONSolidated Standards of Reporting Trials (CONSORT statement; Altman et al., 2001). This means that a checklist and a flowchart (Figures 3 and 6) of the progress through the study were followed to ensure transparent reporting and aid the readers in understanding and interpreting the results.

Table 1. The outline of the papers in the thesis

Paper	Aim	Participants	Design	Outcomes	Time for evaluation
I	To evaluate the use of the internet and computers in a clinically representative group of hearing-aid users.	159	Survey, systematic sampling	internet questionnaire	I. Immediately
II	To validate the questionnaires used online compared with paper-pencil administration.	53	Cross-over	HHIE, IOI-HA, SADL, HADS	I. Immediately II. After three weeks
III	To evaluate the effects of the 1 st version of the online rehabilitation program.	29 (intervention) 30 (control)	RCT	HHIE, IOI-HA, SADL, HADS	I. Pre-study II. Post-study III. Six mth follow-up
IV	To evaluate the effects of the 2 nd version of the online rehabilitation program	38 (intervention) 38 (control)	RCT	HHIE, IOI-HA, HADS	I. Pre-study II. Post-study III. Three mth follow-up

Questionnaires

In the first study, a questionnaire was developed to measure internet, computer and e-mail use by a group of experienced hearing-aid users. The questionnaire contained multiple-choice questions (see Appendix). In addition, some questions regarding demographic characteristics were included in the questionnaire.

In Studies II-IV, four standardized questionnaires were chosen as the outcome measures for perceived hearing aid benefit, satisfaction with hearing aids, perceived activity limitations and participation restrictions.

The selected questionnaires have been shown to be reliable and to have good internal consistency when used with a Swedish population (Öberg et al., 2007; Öberg et al., 2009). All outcome measures were administered using the internet (Andersson et al., 2003; Carlbring et al., 2007).

The HHIE (Ventry and Weinstein, 1982; Lichtenstein et al., 1988) was selected as the primary outcome measure in the intervention studies (Studies III and IV). It contains 25 items and generates two subscales; thirteen questions are designed to examine the emotional consequences of hearing aid use (HHIE-E) and twelve questions are designed to examine the social and situational consequences of hearing aid use (HHIE-S). For each item, there are three potential responses: yes, sometimes, or no. A higher score corresponds to greater perceived activity limitation and participation restriction, the factors that were the focus of the first hypothesis of this study.

The other three questionnaires were selected as secondary outcome measures. The International Outcome Inventory for Hearing Aids (IOI-HA) is a seven-item questionnaire that measures the benefit of hearing aids (Cox et al., 2000; Cox et al., 2002; Cox et al., 2003). Each item focuses on a different topic: (1) daily use, (2) benefit, (3) residual activity limitation, (4) satisfaction, (5) residual participation restriction, (6) impact on others and (7) quality of life. Each item has five potential responses, which range from the worst to the best outcome. A higher score on this questionnaire indicates better outcomes with hearing aids, the factor that the second hypothesis of this study addressed.

The Satisfaction with Amplification in Daily Life (SADL; Cox and Alexander, 1999; Cox and Alexander, 2001) is a fifteen-item questionnaire that measures the benefit and positive effects of hearing aids on a seven-point scale. The questionnaire is divided into four subscales that measure personal image (PI), positive effect (PE), negative feature (NF) and service and cost (SC). Higher scores indicate greater satisfaction and benefit from hearing aids, factors that the second hypothesis of this study addressed.

Moreover, the fourteen-item Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983) was included as a secondary outcome measure. This questionnaire measures the respondent's symptom of anxiety and depression during the week immediately prior to administration. The questionnaire can be divided into two subscales with seven questions each: anxiety (HADS-A) and depression (HADS-D). Each item has four possible responses, with a higher score indicating more symptoms of anxiety and depression.

Participants

In the four studies, a total of 338 hearing-aid users participated on a voluntary basis. Written, informed consent was obtained from all the participants. Data on the participants' age, gender and hearing loss are presented in Table 2.

The participants in Study I were recruited from the Hearing Clinic at Linköping University Hospital. Participants from Study I had the opportunity to participate in Study

II; therefore, the participants in Paper II are partly the same group that was described in Paper I. In Studies I and II, the participants had been diagnosed with a hearing loss and had finished their hearing-aid rehabilitation one year before they took part in the research projects. The defined exclusion criteria were (a) the inability to communicate in Swedish (i.e., the use of an interpreter during the hospital visit) and (b) age below 18 years.

The participants in Studies III and IV were recruited with help from advertisements and articles in national newspapers in Sweden and from specific web pages. The inclusion criteria were that they should experience significant communication problems when using their hearing aids, have access to a computer and the internet and be fluent in written and spoken Swedish.

Table 2. Age, gender and PTA for the study participants.

Study		Age (years)			Gender	PTA, better ear (dB HL)	
		Mean	Range	SD	Men/Women	Mean	SD
I		74	31-96	12	96 / 62	40	15
II	Paper-pencil Q first	67	37-88	10	20 / 6	41	23
	Online Q first	70	36-90	13	20 / 7	31	19
III	Intervention group	66	38-84	12	15 / 13	52	21
	Control group	61	24-76	14	14 / 16	51	26
IV	Intervention group	69	56-80	6	22 / 16	42	12
	Control group	69	26-81	10	22 / 16	42	13

In Studies II-IV, the design of the research project included two test groups. In each study, the participants were randomized by an independent person (not involved in the study or recruitment) for participation in one of the groups.

Statistical Analysis

Means, confidence intervals and standard deviations are presented for all of the studies to provide an overview of the collected sample. Furthermore, the data were analyzed to describe the data and test the hypotheses (Altman, 1999) using the statistical software package STATISTICA (Statsoft, 2011, Version 9). In all studies, the significance level was a p-value < .05.

In Study I, Pearson’s chi-square test (χ^2) and Odds Ratios (OR) were performed. Multiple regression analysis was used to evaluate whether age, gender or hearing loss could predict internet use and how much of the variance that could be explained by those factors.

In Study II, a 2×2 Analysis of Variance (ANOVA) was performed with questionnaire format as the repeated-measure factor. The effect size was evaluated using Cohen's d , internal consistency was evaluated using Cronbach's α and Pearson's product-moment correlations was also used.

In Study III, a 3×2 ANOVA was used with one group factor and two repeated-measures factors and with post hoc tests based on the Bonferroni correction. Additionally, the nonparametric Wilcoxon matched-pair test was performed.

In Study IV, the data were analyzed using Analysis of Covariance (ANCOVA), where T1 or T2 was the dependent variables; group was the categorical factor and T0 as the covariate.

All of the studies have missing data. In Studies I and II, the paper versions of the questionnaires contained skipped questions. In the online versions of the questionnaire, (Studies II, III and IV), it was not possible to skip a question; however, there are still missing data in Studies III and IV because of participants who did not complete all of the assessments. In Studies III and IV, the data were collected with an Intention To Treat (ITT) and the procedure described in Schulz et al. (2011) was used. In Study III, the Last Observation Carried Forward (LOCF) method was used; for example, missing data at T1 were replaced with T0 data (Gadbury et al., 2003; Mallinckrodt et al., 2003; Unnebrink and Windeler, 2001). In Study IV, the missing data at T1 and T2 were imputed using a sequential regression multiple imputation approach (Marwala, 2009) with an assumption that the values were missing at random, meaning that the missing data at T1 and T2 were replaced with imputed data based on the T0 data, missing data at T2 were replaced with imputed data based on the data from T0 and T1 and missing data at T1 were replaced with interpolated data based on the data from T0 and T2 (Moher et al., 2012).

Summaries of the studies

Study I

Aim

To conduct reliable research into online audiology, it is important to determine whether and to what extent adults with hearing loss use the internet. There is a preconception that the internet and online tools are intended for the younger generations only and not for the older ones. In addition hearing loss is a disability which increases with age, consequently one might assume that internet use among the elderly would be low. Access to the internet and the use of computers is increasing over time among the population as a whole, but no data are available that focus on the elderly and/or on people with hearing loss.

In Study I, the aim was to evaluate the use of the internet, computers and e-mail in a clinical group of adults with hearing loss. Further, the study aimed to investigate whether internet, computer and e-mail use differed between genders and among different age groups and to what degree age, gender, education and hearing loss could explain the amount of internet usage. The final aim of Study I was to investigate whether there was a difference in internet, computer and e-mail use between the general population of Sweden (Statistics Sweden, 2008) and a group of adults with hearing loss.

Method

Study I used systematic sampling, in which a selected group of hearing-aid users from the University Hospital in Linköping, Sweden were invited to participate. Every fourth person who had finished hearing-aid rehabilitation in 2008 and who did not meet any of the exclusion criteria were asked to participate in the study via invitation letters sent by regular mail. The defined exclusion criteria were an inability to communicate in Swedish (i.e., patients who used an interpreter during the hospital visit) or age younger than 18 years. Invitation letters were sent by regular mail to a total of 269 individuals. The questionnaire contained nine questions about internet access, e-mail use and education (see Appendix).

Results

The results showed a total response rate of 59%, without any missing data on the questionnaires. Of the respondents, 60% had access to a computer; of those, only one participant did not have access to the internet. Of the participants who used the internet, a clear majority of 83% answered that they used the internet monthly or more often. Half of the participants had an e-mail address and all except seven participants used it daily or multiple days per week. The results showed that significantly more men than women had access to a computer, had access to the internet and used e-mail. The results are in

agreement with general internet use among the Swedish population (Statistics Sweden, 2008), showing significantly higher computer and internet use by men than by women. The results showed that there were significantly more participants in the younger age groups than in the oldest group who had access to a computer and used the internet and e-mail. Approximately fourteen percent of the variance in internet use was explained by age, approximately twelve percent was explained by education and less than three percent was explained by the participant's gender; see Figure 1.

Figure 1. Factors that explain the variance in internet use.

Finally, the results showed significant differences regarding Age Group II (65-74 yrs), whose members had significantly more access to the internet than the people in the general population did and Age Group III (75-96 yrs) in terms of both computer access and internet use, indicating that internet and computer use were more common among younger participants with hearing loss.

Study II

Aim

There are many advantages of using an online format for questionnaires or self-reports, including ease of completion, ease of data handling, lowered risk of data entry errors during transcription, reduced costs and an increased response rate (Coles et al., 2007; Kongsved et al., 2007; Leece et al., 2004). Questionnaires used in audiological research are developed and validated for the paper-and-pencil format. There can be significant differences between questionnaire administration methods that may affect the quality and characteristics of the data (Bowling, 2005). The aim of the study presented in Paper II was to compare the online versus paper-and-pencil administration of four questionnaires measuring hearing-related issues. The questionnaires measured hearing-aid benefit, hearing-aid satisfaction, activity limitations and participation restriction.

Method

In a randomized cross-over design, half of the participants answered the online versions of the questionnaires first and the paper versions second and the other half of the participants answered the questionnaires in the opposite order (Figure 2).

Figure 2. Flowchart of the experiment described in Study II.

The participants were randomized to first complete the questionnaires using paper-and-pencil or via the internet. After three weeks, the participants were retested with the alternate method of administration. The test-retest interval of three weeks was considered short enough to minimize clinical changes but long enough to reduce recall bias.

Results

Of the included participants, 82% completed the questionnaires both on paper and on the internet. Three participants withdrew from the internet portion of the study because of technical problems related to either internet access or other computer problems. Another nine participants did not complete either version of the questionnaires and did not provide a reason for declining to participate.

The results showed a significant main effect of format for the HHIE questionnaire and the effect size of the result was small. Other than this, no significant main effect of group or interaction effects were observed for HHIE. For the remaining questionnaires (IOI-HA, SADL and HADS), no significant main effects of group or format were observed. Furthermore, the results showed no significant interaction effect of group and format. The lack of an interaction effect indicates that the order in which the participants completed the questionnaires did not matter.

Significant correlations between formats were found for all four questionnaires; the strongest correlation was observed for the total score on the HHIE and the weakest correlation was observed for the total score on the SADL. Additionally, the reliability of the internal consistency of the two formats showed negligible differences for each questionnaire. For the HHIE and the IOI-HA, no differences between the internet and paper versions were noted when measured using Cronbach's α .

Study III

Aim

The aim of Study III was to develop and investigate the effects of an online educational program for experienced hearing-aid users. The educational program was an internet course for adults with hearing loss who were experienced hearing aids users but continued to feel limited by their hearing.

Method

The participants learned about hearing, hearing aids, communication strategies and hearing tactics in the course, which was designed as a five-week program. The participants used the book *Fading Sounds* (Elberling and Worsøe, 2005) as course literature and they received weekly home assignments that were related to the book. All information and communication between the course leader and the participants took place on the internet. The results of the tasks were discussed with the test leader via e-mail.

The test group was randomized into two subgroups, an intervention group and a control group, Figure 3. The intervention group attended the internet course described above and the control group was referred to a discussion forum on the internet where they were supposed to share problems and solutions with the other members of the control group. When the participants completed the program, they filled out self-reports (HHIE, SADL, HADS and IOI-HA) again, thus allowing the effects of the internet program to be measured. During a follow-up six months after the participants completed the course, they were asked to complete the same questionnaires again. The data made it possible to evaluate between-participants factors and within-participants factors.

Figure 3. Flowchart of the experiment described in Study III.

Results

The results showed a significant decrease in activity limitation and participation restriction (HHIE) for both groups, while the more detailed breakdown showed that the participants in the intervention group improved more than those in the control group. At the follow-up six months after the study, the results showed that the significant decrease in activity limitation and participation restriction (HHIE) was maintained, while the interaction effect of the immediate results had lost significance, Figure 4.

Overall, the results from this study showed that it is possible to use online tools during the rehabilitation process for older hearing-aid users. The practical setup of using the internet for interactions with the population in question succeeded because almost all of the participants completed the online tasks. The two forms of intervention that were applied, (1) rehabilitative online education and interaction with professional audiologists and (2) peer group online discussions, had positive rehabilitation effects, though not in entirely similar outcome domains. It is suggested that combining elements of both approaches may provide more comprehensive rehabilitation without losing the benefits of either approach.

Figure 4. Results of self-reported hearing-related problems in terms of activity limitation and participation restriction (HHIE) before and after the intervention and at the six-month follow-up (mean and SD).

Study IV

Aim

The study presented in Paper IV was a further development of the online, educational, rehabilitative program described in Paper III. The online educational program and the experimental setup were improved to provide more comprehensive outcomes for the program. The overall aim and structure was the same as in Paper III, i.e., a five-week online educational program for experienced hearing-aid users who subjectively reported a high degree of hearing-related handicap.

Method

Similar to the setup of Study III, the participants had to read some material, they had weekly contact with professional audiologists and they had contact with each other via an online discussion forum. The focus was on combining education, which consisted of information-based rehabilitation and problem-solving exercises, with peer discussion, Figure 5.

Figure 5. Overview of the flow of the elements included in the 2nd version of the online program.

The program was expanded based on the results and experiences drawn from Study III, with inspiration and some parts drawn from the program developed by Hickson and colleagues (Hickson et al., 2006; Hickson et al., 2007, Öberg et al., in press) and also with information regarding psychosocial-related situations, such as cognition, memory and applied relaxation tasks (Johansson et al., 2012; Pichora-Fuller, 2007).

Table 3. Overview of the topics included in the 2nd version of the online program (Study IV).

Main content	Subcontent	Reference
Introduction		
Anatomy & physiology		Elberling and Worsøe (2005)
Hearing knowledge	Hearing aids	Elberling and Worsøe (2005)
	Five dimensions of hearing	
Communication training	Conversation in disturbing background noise	Hickson et al. (2007)
	Conversation at home	
	Communication strategies	
	Good advice when you are talking to...	
Problem-solving in general		Hickson et al. (2007)
Applied relaxation		Johansson et al. (2012)
Assistive listening devices		Hickson et al. (2007)
Planning for how to maintain behavioral changes		Johansson et al. (2012)
Final advice		Hickson et al. (2007)

The participants in the control group were on a waiting list; in the meantime, material about the history of hearing aids (Nielsen, 2008) was sent for them to read. Three months after T1, the participants had to fill out the same self-reports online for a third time. The responses to the questionnaires at this time point were used to measure the effects three months after the educational program was finished, Figure 6.

Figure 5. Flow chart of the experiment described in Study IV. The grey boxes indicate the differences between the 1st and 2nd RCT.

Results

The overall result showed that the intervention group was moving toward being less affected by their hearing limitation after the online educational program than they were before the program, while the control group's subjective reports of hearing problems were not reduced to the same degree, Figure 7.

The results showed a significant difference at T1 between the intervention group and the control group on the total score of the HHIE and on the social and emotional domain subscales. This between-group effect indicates that participants in the intervention group experienced significantly decreased participation restrictions and activity limitations at T1 and that the improvements were enhanced and maintained at T2 compared with the participants in the control group. In the analyses, T0 was used as a covariate; therefore, the results cannot be explained by initial differences between the groups.

Figure 6. Results of self-reported hearing related problems in terms of activity limitation and participation restriction (HHIE) before the study, after the study and at the three-month follow-up (mean and SD).

The secondary outcome measures used in the study were the IOI-HA and HADS. The total score from the IOI-HA did not show any significant differences after the study or at the three-month follow-up. However, significant differences emerged in specific subscales of the IOI-HA. For *Residual Participation Restrictions*, participants in the intervention group showed improvement after the study while the control group did not; however, the results did not persist at the three-month follow-up. For *Impact on Others*, the intervention group improved after the study, while the control group did not improve and these results persisted at the three-month follow-up.

In the other secondary outcome measure, the HADS, showed a significant between-group effect at the three-month follow-up, but not directly after the study. The results show that the total score of the HADS did not change in the intervention group after the study, but at the three-month follow-up, the scores improved. The scores of the participants in the control group did not change after the study or at the three-month follow-up. A significant between-group effect was found for the depression domain (HADS-D) at the three-month follow-up but not after the study. The results indicate that the participants in the intervention group improved their scores on the depression scale at the three-month follow-up, whereas the participants in the control group did not. Finally, a significant

between-groups effect was found for the anxiety domain (HADS-A) at the three-month follow-up but not after the study. The results indicate that the participants in the intervention group improved their scores on the anxiety scale at the three-month follow-up, whereas the participants in the control group did not.

GENERAL DISCUSSION

The main purpose of this thesis was to evaluate how modern technology can be used in the rehabilitation process of people with hearing loss. To use modern technology effectively, it is important to gather information regarding how this population (hearing-aid users and people with hearing losses) uses modern information technology. There are still preconceptions that elderly people, many of whom have hearing losses and are hearing-aid users, are not using information technology such as computers, the internet and e-mail. The results from the first study (Paper I) could not confirm such preconceptions. On the other hand, the results showed that the population we were interested in uses these kinds of technology to the same degree that the general population of Sweden does. It was also necessary to validate online formats of the most commonly used self-reports in order to evaluate the use of online rehabilitation tools. That requirement led to the second study (Paper II), in which the results showed that a group of hearing-aid users rated their outcomes the same way both on paper-and-pencil and online. There was one exception: the HHIE questionnaire, on which the participants scored significantly higher on the online format than on the paper-and-pencil format. In the two main studies, two different editions of an online rehabilitation program were evaluated by two different groups of hearing-aid users. The main outcome from the two online rehabilitation studies (Paper III-IV) was that it is feasible to use online tools during the rehabilitation process. Even more importantly, the studies showed that the participants decreased their activity limitations and participation restriction significantly, although they already had gone through an audiological rehabilitation, including hearing aid fitting.

Hearing-aid users and modern information technology

There are few studies in the literature that have evaluated and documented the use of information technology in people with hearing loss or hearing aids. A few previous studies report that information technology use by the elderly is not very high (Eek and Wressle, 2011; Selwyn, 2004; Selwyn et al., 2003) and it is particularly low among hearing-aid users (Henshaw et al., 2012). In Study I, the level of information technology use in the group of hearing-aid users was not lower than it was among the general population of Sweden. This can be interpreted in light of the fact that modern technology usage is higher in Sweden than it is in many other countries (i2010 - Annual Information Society Report, 2007). More importantly, however, the current rate of users indicates that the proportion of technology users will most likely increase in just a few years, especially among the focus group of this thesis, hearing-aid users and the elderly.

Not surprisingly, the outcome of the first study (Paper I) showed that there are gender differences in the usage of modern technology; namely, that more men than women have and use computers, the internet and e-mail (Henshaw et al., 2012; Sweden Statistics, 2008). The final interesting outcome of the first study was the degree to which different factors, such as age, gender, hearing loss and education, could explain the use of modern information technology. The highest usage of the internet was seen among the youngest age group and males with higher education levels and the lowest usage was among the elderly and women with less education. These results are consistent with newly reported findings from Henshaw et al. (2012) who investigated the association between age, socioeconomic status and gender due to self-reported usage of computers and the internet. The findings are also in line with reports of general Internet use in the Swedish population (World Internet Project International Report, 2013) showing that age, gender and education still have a strong association with internet use, especially among the elderly.

The reasonable overall interpretation of the first study is that people using hearing aids are using modern information technology like computers, the internet and e-mail. Thereby can these be useful tools to help the elderly with hearing loss obtain access to rehabilitation from home (Henshaw et al., 2012; Kaye, 2000).

Questionnaire format comparison

In the second study the reliability across formats of four different questionnaires that commonly are used in hearing aid rehabilitation and hearing research was evaluated. Previous research has evaluated some of the questionnaires in an online format, but for a population that was not similar to hearing-aid users (Carlbring et al., 2007).

The result of Study II showed that hearing-aid users are willing and able to fill out questionnaires online. An unexpected outcome of the study was the observed gender effect related to using modern technology such as computers and the internet. The invitation letters were sent out to an equal number of men and women and a majority of the responses were from men (80%). This can be interpreted to indicate that the men in this population are more willing to use the internet and the result mirrors those of Study I, in which an outcome of the data was an expected and similar gender effect, showing that men have more access to modern technology than women have.

The main outcome of the second study was the finding of no order effects for format presentation. The lack of order effects indicates that it did not matter whether the participants filled out the online or the paper-and-pencil versions of the questionnaires first. Similar studies have been performed with other target groups (Andersson et al., 2003; Holländare et al., 2010) and a similar absence of an order effect was shown.

One questionnaire, the HHIE, yielded different results from the others. The psychometric results for the HHIE questionnaire were consistent with what has been reported in previous studies that used the paper format of the questionnaire (Stark and Hickson 2004; Öberg et al., 2007). A significant main effect of format showed that the participants in general rated a higher score of 3.9 points on a scale of 100 in the internet format than in the paper-and-pencil version. Earlier studies have hinted that participants may reveal more about themselves when communicating via a computer (Joinson, 1999). This might explain the higher degree of hearing difficulties reported by participants using the online format compared with the paper format. Because the effect size of the difference between the two formats was small, the results were interpreted to indicate that the actual relevance of the difference depends on the context in which the questionnaire will be used (Weinstein et al., 1986). Buchanan's suggestion (Buchanan, 2002) that separate norms should be derived for internet-based and paper-based questionnaires may also be relevant for hearing-related measures and may be important in relation to the HHIE questionnaire.

Other statistical tests of reliability of the data showed good results for all four of the questionnaires in both formats.

The three-week interval between questionnaire administrations may have lowered the correlations for the HADS questionnaire because separating the administration dates required the participants to report their moods for two different weeks (Wijndaele et al., 2007). The interval between Test 1 and Test 2 was determined to be short enough to exclude clinical change, but long enough to reduce recall bias. It is likely that the length of the interval between the two measurement times could affect the questionnaire results; this is something that future studies could evaluate and examine further.

Online Rehabilitation Programs

The main purpose of this thesis was to develop audiological rehabilitation program and evaluate it in online versions. As the rehabilitation system is constructed in many countries today, many people with hearing loss are not receiving the kind of treatment they need to be able to use their hearing in the best possible way. Sanders (1971) stated that the level of hearing loss severity is not the determinant of who should or should not receive extended rehabilitation (e.g., intervention beyond hearing aids). When using online tools and internet supported rehabilitation in a cost-effective way, more people and more patient categories could have contact with prolonged rehabilitation programs that would include more than fitting hearing aids. The programs evaluated in this thesis were not directed toward participants with severe hearing loss, but to those with a typical moderate hearing loss that is normally compensated by hearing aids, but who continued to experience residual hearing loss.

The two online rehabilitation studies differed both in their design and in the content of the programs. Both studies used a randomized controlled study design and both online courses lasted for five weeks. The CONSORT statement (Altman et al., 2001) was followed throughout both studies to generate transparent reporting; therefore, the interpretation of the findings should be straightforward and easy for readers to follow. In the first RCT, an active control group was used, whereas in the second RCT, a waiting-list group was used. In the second RCT, the participants in the control group were given the opportunity to take the online course after the intervention group had finished it. For ethical and practical reasons, it was not possible to delay the control group's access to the course; therefore, the follow-up in the second RCT occurred earlier than it did in the first RCT, in which the participants in the control group were never given the opportunity to take the course. The participants in both RCTs were treated on ITT basis. In the first RCT, the method of LOCF was used and in the second RCT, the multiple imputations method was used. There is no consensus about which method to use when handling missing data (Moher, 2012); therefore, the context of the study and the statistical methods used must determine which model to apply. In the later study, the multiple imputations method was preferred to avoid miscalculating the variability of the results and use all of the data from the experiment (Little et al., 2012).

The second RCT featured a more extended program than was used in the first RCT, as more reading, more assignments and more opportunities (e.g., being active in an online discussion forum) were provided. The incitement for developing the online educational program and the experimental setup of the study was to enhance the outcomes of the program. The findings of the first RCT encouraged the development of parts of the online program to better meet the needs of people with persistent hearing problems and to include evidence-based tools (Wong and Hickson, 2012) developed to achieve the goals of audiological rehabilitation and thereby improve the users' activity limitations and participation restrictions.

In the first RCT, the participants of the control group, who participated in the online discussion forum, showed an improvement in the primary outcome measure, even though they had contact only with peers and never with any professionals. When looking at the activity in the control group it was noticeable that the participants exposed their problems and solutions to each other in a very friendly and constructive way. The high level of activity and constructive help evident here was not expected due to results from earlier studies that used a discussion forum in the control group (Andersson, 2009). Given that the control group received an active intervention, it is most likely not surprising that participants in that group showed improvements on the primary outcome measure, HHIE because they were actively participating in discussions and could learn from each other.

In the second RCT when the discussion group was made a part of the intervention, the participants were not as active in the forum as they were in the control group in Study III. Perhaps this has to do with the setup of the study and the circumstances. In future studies it might be considered to have a more tailored setup of the program and thereby have more individualized versions of the intervention. It can be concluded that it is challenging to design the setup of a control group. The essence of the control group is e.g., to measure placebo effects of the evaluated treatment or measure training effects of the used outcome measures.

The first RCT provides evidence that the internet can be used to deliver education to experienced hearing-aid users who report residual hearing problems such that their problems are reduced after the intervention. The mentioned study was the first study evaluating online rehabilitation for hearing-aid users and it describes a proof of concept, by using the internet in a group of hearing-aid users. The study was also an attempt to test which kind of elements that should be included in an online audiological rehabilitation program. The results indicated that both interaction with professional audiologists and interaction with peers affected the participants' activity limitations and participation restriction up to six months after finished online education.

In the second RCT the participants of the intervention group decreased their HHIE scores on average by fifteen points when comparing the initial score and the three-month follow-up. The magnitude of the increased HHIE score can be compared with other studies where the HHIE was used as an outcome measure for hearing aid interventions. Our results are in line with the findings of McArdle and colleagues, who reported an average decrease in the HHIE score of eighteen points (McArdle et al., 2005). Furthermore, Öberg and colleagues also showed an improvement of eighteen points on the HHIE in a group of first-time hearing-aid users who had some initial pre-training (Öberg et al., 2008). Our participants were not first-time users of hearing aids; on average, they had used hearing aids for eight years. During the time of the study and afterwards, we did not have any physical contact with the participants or their hearing aids and we did not carry out any adjustments of the participants' hearing aids. Nonetheless, our participants experienced improvements in the domain of activity limitations and participation restrictions as if they had completed a hearing-aid intervention.

Outcome measures for Online Rehabilitation Program

The use of HHIE as a primary outcome measure in a context like this is worth considering. Hearing aid fitting interventions can show large pre-post improvements on HHIE (see, for example, Öberg et al., 2008), but the HHIE measurement has been used with varying success when evaluating rehabilitation programs. Abrams et al (1992) showed positive

improvements by using HHIE when evaluating counseling in the clinic, while Cherry and Rubinstein (1994) could not see any positive effects in the HHIE scores when using HHIE in a telephone follow-up, neither could Kricos and Holmes (1996) when they used HHIE in a comparison of two different rehabilitation programs with a control group. In this study, our group of participants was used to hearing aids but still experienced problems related to their hearing loss. In future studies it might be more appropriate to have a goal in consideration of how people are using their hearing in different situations instead of focusing on what they cannot hear due to their hearing loss.

The IOI-HA is often used as a self-reporting instrument in research concerning hearing aid use partly because it is translated and evaluated in many languages (Cox et al., 2000). The pre-intervention results in the two RCTs are in line with published results from other Swedish studies (Brännström and Wennerström, 2010; Öberg et al., 2007), where hearing aid rehabilitation has been evaluated using the IOI-HA. The outcome of the data is therefore that the participants in the RCT studies were neither more nor less satisfied with their hearing aids before they took part in the online rehabilitation program than general hearing-aid users in Sweden after completing ordinary hearing aid rehabilitation. In the first RCT, no effects of the intervention based on the IOI-HA were detected and the interpretation was therefore that the IOI-HA did not catch the components that were included in the online rehabilitation program. In the second RCT was significant effects of measurable improvements at two items of IOI-HA (*Residual Participation Restrictions* and *Impact on Others*) detected directly after the online program, but the effects were only maintained at the follow-up for one of the items (*Impact on others*). The participants in the intervention group rated the measures significantly higher after completing the online program than they did before, whereas the participants in the control group did not. A significant improvement in the scores for *Residual Participation Restrictions* can be interpreted as evidence of effects in the domain of participation restrictions (Cox et al., 2003). The interpretation of the IOI-HA results is that it catches some of the components that were included in the revised online rehabilitation program. Kramer and colleagues (Kramer et al., 2005) used the IOI-HA when evaluating a home training program directed to hearing-aid users and they showed some improvements consistent with the results in the second RCT. Other studies have been unable to demonstrate the significant effects of an intervention of audiological rehabilitation when using the IOI-HA (Saunders and Forsline, 2012) and it has been argued that it is difficult to show the impact of an intervention on hearing aid satisfaction using the IOI-HA (Lundberg et al., 2011). The outcomes from the SADL questionnaire in the first RCT were difficult to interpret in the direction that the questions did not catch the factors that we influenced by the content of the online rehabilitation program and therefore we decided to not include it in paper IV.

The findings in the first and second RCT show that taking part in an online rehabilitation program would have significant positive consequences regarding psychosocial wellbeing, captured by the outcome measure HADS. It seems that the HADS is sensitive enough to detect changes in the psychosocial domain after this type of intervention and the effects differ depending on the content of the online program. The results can be interpreted as a result of that the participants in the second RCT obtain a confirmation from the peers and the professional audiologists in the direction that they feel less of symptoms of anxiety and depression that otherwise can be identified when hearing loss not are corrected (Andersson et al., 2009; Erdman, 2009; Arlinger, 2003). The results indicate the importance of additional research on the long-term effects of online rehabilitation so that the results for hearing-aid users can be sustained over time.

Reflections

In the first and second study (Papers I and II), gender effects were identified that showed that more men than women answered that they were using modern technology such as the internet and that more men than women were willing to participate in research that included the internet. This was interpreted to indicate that the men in this population were more willing than the women to use the internet. In the two RCTs (Papers III and IV), the participants were recruited via advertisements in newspapers and in both RCTs, close to an equal number of men and women showed interest and participated. The overall interpretation of gender effects and internet access seems therefore to be in the direction that there are no significant gender-related differences related to the use of online tools (i.e., rehabilitation programs) when individual achievement is possible. Some of the participants commented that they had integrated what they had learned in terms of communication strategies into their everyday lives and that old knowledge was refreshed and extended after they participated in the online program. Other participants commented that they learned a new vocabulary from the course that improved their conversations with their audiologist. The positive effects of using online tools in the rehabilitation program include the possibility of individualizing the program so each participant obtain as much as possible out of it.

Limitations

In the included studies, some limitations have been identified. The conclusions from all studies are drawn from a selected sample of hearing-aid users.

The data presented in Paper I can be seen as a reflection of the present, but the reported use of information technology typically continues to increase over time, especially among elderly people (Internet World Stats, 2013). Determining the internet, computer and e-mail use in the group of non-respondents could, however, provide interesting information. We

had a response rate of 59%, with no missing data on the questionnaires, which we consider rather good because the majority of our participants were elderly. It is not always optimal to mail questionnaires to elderly people because a high rate of missing data and a lack of willingness to fill out questionnaires have been reported (Smeeth et al., 2001).

In the second study, a clinical sample answered the questionnaires. However, possession of an e-mail account was required for participation in the study. This requirement limits generalizability because the results from this experiment can only be generalized to adults with hearing loss who have some type of regular internet activity, even though this sample was clinically representative. Including more female participants in the present study would have improved the generalizability of the conclusions.

In the two RCTs, the participants were recruited according to their own interest through advertisements, articles and information on web pages. Therefore, there are no indications that the sample mirrored the general group of hearing-aid users. The included participants were highly motivated to take the course; they were well educated, they had been hearing-aid users for some years and in the first RCT, they were also younger than the general population of hearing-aid users in Sweden. These characteristics might have led to fewer drop outs than would have occurred if a more clinically representative sample of hearing-aid users had participated. A study of other internet treatments for other disability groups (anxiety, social phobia) concluded that the self-selected participants were indeed more representative of the given group than the clinical group was (Titov et al., 2010). It cannot be said that the programs described in this thesis fit all hearing-aid users; it could be assumed that such programs best fit those who enjoy reading and getting information by themselves. However, the internet is a very useful medium and in the future, it could be customized to meet individual needs and possibilities. Hearing clinics need to have rehabilitation programs that are useful for all of their clients. The programs that were evaluated in this thesis could be seen as complementary to the audiologist's selection of rehabilitation programs.

Future directions

The coming generation of potential hearing-aid users is expected to experience higher demands on physical health and a greater need for technical solutions. Hearing problems will affect this population in many everyday situations and they will have high requirements for their hearing.

In the future, further developments should make it possible to combine hearing-aid fittings and education about hearing-aid related subjects using the internet as a platform. By using new methods and technology (i.e., the internet) in the rehabilitation of people

with hearing loss, new groups of potential hearing aid clinic patients might become more motivated to begin rehabilitation. It would be possible to actively incorporate significant others into the program and experienced hearing-aid users' satisfaction levels may increase.

There is a need for additional research, further development and evaluation of rehabilitative online interventions similar to the one described in this thesis. Future work should focus on investigating program details and further development, thereby explaining how individual elements of the online program are responsible for the effects. In addition, methods to tailor the program based on hearing-aid users' individual needs and desires to achieve self-empowerment, as described by Kricos (2006), should be investigated.

Audiological rehabilitation from a distance, or teleaudiology, is described as a concept of a new era (Swanepoel et al., 2010). This concept includes the improvements in audiological rehabilitation that are described in this thesis as well as hearing screening, diagnosis and interventions including hearing aid fitting. One can certainly expect a wide variety of innovations within this concept in the future making teleaudiology a much needed spearhead for bringing better and more efficient rehabilitation to hearing-aid users.

CONCLUSIONS

The conclusions of this thesis can be summarized as follows:

Hearing-aid users use computers, the internet and e-mail overall at the same level that the general Swedish population does. In some specific age groups, this usage is even higher among hearing-aid users than among the general population.

It is possible to use online versions of questionnaires that often are used in hearing research and clinical situations because responses remained consistent across administrations and formats for three of the four included questionnaires. It is recommended that the administration format remain stable across survey time points.

It is possible to use online tools during the rehabilitation process for older hearing-aid users. The practical setup of using the internet to interact with the population in question succeeded, as almost all of the participants completed the computerized exercises. The results of this thesis support the idea that in the near future, the audiological rehabilitation process is likely to include the internet and that some elements of rehabilitation and contact with professionals can occur via the internet using communication tools such as e-mail.

Participation in a structured online rehabilitative education program had positive effects on hearing-aid users' participation restrictions and activity limitations that persisted three months after the program was completed.

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No man is an Island, entire of it self; every man is a piece of the Continent, a part of the main.

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SVENSK SAMMANFATTNING

Internetinterventioner för personer med hörselnedsättning – undersökning av rehabilitering, självskattningsformulär och användandet av internet hos hörapparat-användare

Ungefär fem procent av världens befolkning har någon form av hörselnedsättning och därmed är hörselnedsättning en av de vanligaste funktionsnedsättningarna. Sannolikheten att drabbas av en hörselnedsättning ökar med stigande ålder och hos personer som är äldre än 65 år har ca en tredjedel någon form av hörselnedsättning. Detta gör att hörselnedsättning är ett funktionshinder som drabbar majoriteten av världens befolkning på ett eller annat sätt, då man antingen själv utvecklar en hörselnedsättning eller för att en anhörig upplever konsekvenserna av den. Förutom de direkta och uppenbara, negativa effekterna av en hörselnedsättning, som till exempel svårigheterna att uppfatta tal, musik och andra (svaga) ljud, så finns det också ett antal indirekta negativa konsekvenser i form av psykologiska och psykosociala faktorer som blir påverkade. Många personer med nedsatt hörsel upplever svårigheter med kommunikation vilket kan ha en betydande inverkan på vardagen och livskvaliteten, vilket i sin tur kan leda till känslor av ensamhet, isolering och frustration, särskilt bland äldre personer med hörselnedsättning. För personer i yrkesverksam ålder kan effekterna yttra sig som problem med att hantera vissa arbetssituationer men även i form av negativa influenser i relation med make / maka när missförstånd och inaktivitet i samtalen ökar.

Den vanligaste och mest accepterade hjälp du kan få när du har en diagnosticerad hörselnedsättning är en audiologisk rehabilitering där hörapparaterna är en central del i behandlingen. Dagens avancerade hörapparater hjälper i många svåra kommunikationssituationer, men det är känt att avancerade hörapparater ofta inte är tillräckligt för att uppnå en fullständig rehabilitering. Resultatet av det är att många hörapparat-användare inte använder sina hörapparater och inte är tillräckligt nöjda med sin situation på grund av kvarstående hörselproblem.

I framtidens hörselvård kommer det med stor sannolikhet att ingå moment i rehabiliteringen av vuxna med hörselnedsättning där vissa verktyg är tillgängliga via internet. Därför är det viktigt att undersöka om, och i vilken utsträckning vuxna med hörselnedsättning använder internet, för att därmed kunna avgöra vilka förväntningar man kan ha på införandet av internetbaserade verktyg i hörselvården.

När man utvärderar effekterna av hörselrehabilitering används ofta olika sorters frågeformulär. De frågeformulär som används inom audiologisk forskning och på hörselkliniker har utvecklats och validerats för att användas med papper och penna. För att kunna använda motsvarande frågeformulär, via internet istället för med papper och penna, är det nödvändigt att utvärdera dem i det formatet och jämföra resultaten mellan formaten. Det vill säga, svarar man på samma sätt oavsett om man svarar på papper eller via internet.

Användandet av internet i den audiologiska rehabiliteringen ger många fördelar då man på ett kostnadseffektivt sätt kan inkludera ytterligare komponenter, så som att informera och vägleda användare med hörapparat om kommunikationsstrategier, hörseltaktik och hur man hanterar hörapparaterna. Genom att utveckla internetbaserade rehabiliteringsprogram, kan det vara möjligt att lära personer med hörselnedsättning nya sätt att hantera svåra kommunikationssituationer så att man upplever sina hörselrelaterade problem som mindre besvärande.

Syftet med denna avhandling var att undersöka möjligheterna att använda interaktiva verktyg i rehabiliteringsprocessen för vuxna hörapparat-användare. I avhandlingen ingår fyra olika studier och totalt har 338 personer med hörselnedsättning deltagit i studierna.

I den första studien undersöktes det om, och i vilken utsträckning vuxna med hörselnedsättning använder sig av internet, e-mail och datorer. Studien var utformad för att avgöra om hörapparat-användare använder modern teknik som internet och datorer annorlunda än den genomsnittliga befolkningen i Sverige. En grupp bestående av vuxna med hörselnedsättning, tillfrågades om hur de använder internet, dator och e-mail och resultaten jämfördes med hur genomsnittsbefolkningen i Sverige (data från Statistiska Centralbyrån) använder sig av motsvarande verktyg. I den andra studien utvärderades formatet av fyra standardiserade frågeformulär som ofta används i hörselforskning och på hörselklinik på det viset att deltagare först fick fylla i frågeformulären på papper och därefter på internet. Avslutningsvis genomfördes två randomiserade, kontrollerade studier med syfte att utvärdera ett internetbaserat rehabiliteringsprogram. Rehabiliteringsprogrammet varade över en fem-veckors period och det var avsett för vuxna, erfarna hörapparat-användare. I rehabiliteringsprogrammet ingick olika moment, självstudier och professionell vägledning av en audionom. Effekterna av det internetbaserade rehabiliteringsprogrammet jämfördes med en kontrollgrupp som antingen deltog i ett diskussionsforum utan någon professionell kontakt (Studie III) eller väntade på att få delta i studien (Studie IV).

Resultaten från studierna visade att en majoritet av de hörapparat-användare som deltog i studie I använder sig av datorer, internet och e-mail. Resultaten visade också att deltagarna i studien använde datorer, internet och e-mail i samma utsträckning som genomsnittsbefolkningen i Sverige gör. Men bland de äldre deltagarna i studien var det fler som använde internet, dator och e-mail jämfört med genomsnittsbefolkningen i Sverige. Vidare visade resultaten i Studie II att i ett av de frågeformulär som användes uppmättes en skillnad i svar beroende på om deltagarna fyllde i formuläret via internet eller på papper. Deltagarna rapporterade i genomsnitt att de hade något mer besvär av sina hörselrelaterade problem när de svarade via internet än när de svarade på pappersversionen av samma frågor. Skillnaden mellan formaten var statistiskt säkerställd, men skillnaden i sig så liten att den troligen inte har någon klinisk relevans. I de andra tre frågeformulären som ingick i studien gick det inte att visa några skillnader beroende på vilket format som användes.

I de två studierna som utvärderade ett internetbaserat rehabiliteringsprogram gick det att mäta positiva effekter i behandlingsgruppen, i form av ökad delaktighet efter respektive kurs var avslutad, men resultaten var något olika i de två studierna. I den första studien upplevde deltagarna i både behandlingsgruppen och kontrollgruppen att de hade mindre besvär av sina hörselrelaterade problem och att de därmed upplevde mer delaktighet efter att studien var slut jämfört med innan de deltog i studien. Resultaten höll i sig vid en uppföljningsmätning sex månader efter att studien hade avslutats. Även effekter i psykosociala domäner kunde uppmätas. I den andra internetbaserade rehabiliteringskursen visade behandlingsgruppen på mindre besvär av sina hörselrelaterade problem och upplevde därmed mer delaktighet när kursen var avslutad än innan de deltog i studien och de resultaten kvarstod och hade till viss del förstärkts vid en uppföljningsmätning tre månader efter kursens avslut. Även betydande förbättringar på området för det psykosociala välbefinnandet kunde uppmätas vid tre månaders uppföljning. Däremot förbättrade sig inte deltagarna i kontrollgruppen på motsvarande vis, då de värderade sina hörselrelaterade problem att vara lika stora hela tiden.

Slutsatserna från denna avhandling kan sammanfattas på följande sätt;

Hörapparat-användare använder datorer, internet och e-mail, i samma grad som den allmänna svenska befolkningen, i vissa åldersgrupper är denna användning högre bland hörapparat-användarna än i den allmänna befolkningen.

Det är möjligt att använda enkäter som ofta används i hörselforskning och kliniska situationer, via internet då deltagarna svarade konsekvent i de två formaten (internet vs. papper) för tre av de fyra inkluderade enkäterna. Rekommendationer till följd av resultaten i studien är att man bör vara konsekvent och använda sig av samma format genom en behandling, undersökning eller i ett forskningsprojekt.

Resultaten i studien tyder på att det är möjligt att använda vissa verktyg i rehabilitering av personer med hörselnedsättning via internet. Den praktiska delen av studien gav lyckade resultat då nästan alla deltagare genomförde programmet via internet. Resultaten i denna avhandling stöder tanken att, inom en snar framtid, kan man förvänta sig att det ingår delar i den audiologiska rehabiliteringen via internet, t.ex. kontakt med professionella via e-post.

Med hjälp av ett strukturerat, internetbaserat rehabiliteringsprogram upplevde hörapparat användare mindre besvär av hörselrelaterade problem än de gjorde innan de deltog i studien. Studien är den första i sitt slag och innehåll och utformning av de internetbaserade rehabiliteringsprogrammen behöver ytterligare utvecklas och utvärderas innan de kan användas i klinisk verksamhet.

APPENDIX

Questions

In this research study, we want to identify how people with hearing impairments use computers and the Internet. Below you will find nine questions and we ask you to check the box in front of the answer you agree with most.

1. Do you have a computer at home?
☐ Yes ☐ No
2. Do you have access to a computer outside your home (e.g. at work, library etc.)?
☐ Yes ☐ No
3. Do you have access to the Internet?
☐ Yes ☐ No
4. Do you search information via the Internet?
☐ Yes ☐ No
5. If your answer was "yes" on Q4; how often do you use the Internet?
☐ Daily ☐ Weekly ☐ Monthly ☐ Very seldom
6. Do you have an e-mail adress?
☐ Yes ☐ No
7. Do you use your e-mail adress?
☐ Yes ☐ No
8. How often do you use e-mail?
☐ Daily ☐ Weekly ☐ Monthly ☐ Very seldom
9. What is your last completed education
☐ Elementary School ☐ High School ☐ University

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