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Avancerad nivå

Titel
Undersökning av förutsättningarna att utveckla ett frågeformulär utifrån ICF 2001 som utvärderar självupplevd delaktighet i hörselkrävande situationer.

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Sammanfattning på svenska.

Syfte: Syftet med studien är att utifrån *International Classification of Functioning, Disability and Health* (ICF, WHO 2001) undersöka förutsättningarna för att utveckla ett frågeformulär på svenska för skattning av självupplevt deltagande i hörselkrävande situationer (DHS). Detta då WHO numer har ersatt *International Classification of Impairment, Disability and Handicap (ICIDH)* från 1980 med ICF 2001, där termen ”handikapp” omdefinierats till ”delaktighet”.

Metod: Efter litteraturstudier i PubMed valdes frågeformuläret ”Rating of Perceived Participation” som mall till DHS. DHS mäter fyra för rehabiliteringsprocessen viktiga utfallsvariabler: (1) patientens självupplevda grad av delaktighet i olika hörselkrävande situationer, (2) patientens egen tillfredsställelse med sitt deltagande i dessa situationer, (3) egen önskan om stöd om att förändra sin grad av delaktighet, samt (4) patientens egna prioriteringar av de situationer där hörselrehabiliteringen främst skall ge en ökad delaktighet. DHS giltighet (content validity) bedömdes av såväl patienter som en expert panel bestående av olika inom hörselvården specialiserade yrkesgrupper.

Pilotstudie: DHS evaluerades i en pilotstudie, där totalt 29 män och 21 kvinnor med olika grader av presbycusis deltog. Ton- och talaudiometri utfördes. Fyra frågeformulär (DHS, Hearing Handicap Inventory for the Elderly, Communication Profile for the Hearing Impaired, Hearing Handicap and Support Scale) fylldes i två gånger med fyra veckors mellanrum. DHS utvärderades enligt gängse statistiska metoder.

Resultat: DHS:s reproducerbarhet var hög, liksom internal consistency och convergent validity, medan predictive validity var måttlig.

Slutsats: DHS har goda förutsättningar för att kunna utvecklas till ett mätinstrument med hög tillförlitlighet att användas inom hörselvården såväl i Sverige som internationellt.

Nyckelord: Hearing loss, Participation, ICF, Rehabilitation, Questionnaire, Measurement

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MASTER RESEARCH THESIS IN AUDIOLOGY, 30 ECTS

Advanced level

Title
Investigation of the prerequisites for the development of a measuring instrument assessing perceived participation in hearing demanding situations under the ICF 2001.

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Abstract

Objective: The aim of the current study is investigate the prerequisites for designing a questionnaire in Swedish based on the *International Classification of Functioning, Disability and Health (ICF) by the WHO (2001),* for estimation of perceived participation in hearing demanding situations (DHS). The questionnaires presently used in Audiology emanate from the *International Classification of Impairment, Disability and Handicap,* which was launched in 1980. In the ICF, the term "handicap" has been replaced to "participation".

Method: After a literature search in PubMed, the questionnaire “Rating of Perceived Participation” was selected as base to DHS. DHS measures four variables important for the rehabilitation process: (1) the patient’s perceived participation in difference situations, (2) the patient’s satisfaction with the present participation level, (3) the patient’s own desired wish for support to change the level of participation, (4) the patient’s selection of the situations where improvement is most desired. The content validity was assessed by both patients and aslo expert panel consisting of different audiological professionals.

Pilot study: DHS was evaluated in a pilot study comprising a total of 29 men and 21 women with different level of presbycusis. Pure tone and speech audiometry was conducted. Four questionnaires (DHS, Hearing Handicap Inventory for the Elderly, Communication Profile for the Hearing Impaired, Hearing Handicap and Support Scale) were filled in twice four weeks apart. DHS was evaluated according to statistical standard methods.

Results: The DHS showed a high reproducibility, internal consistency and convergent validity, but a moderate predictive validity.

Conclusion: DHS has good potential of becoming a measurement scale with high accuracy, to be used in Audiology both in Sweden as well as worldwide.

Key words: Hearing loss, Participation, ICF, Rehabilitation, Questionnaire, Measurement

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STUDY II: CONSTRUCTION AND EVALUATION OF A DISEASE-SPECIFIC, ICF-BASED QUESTIONNAIRE "PARTICIPATION IN HEARING DEMANDING SITUATIONS"

ABBREVATIONS

APHAB:	Abbreviated Profile of Hearing Aid Fitting Benefit
CPHI/CSS:	Communication Profile for the Hearing Impaired / Communication Strategi Scale
DHS:	Delaktighet i hörselkrävande situationer
HF-PTA:	Pure tone average at the 3000, 4000 and 6000 Hertz frequencies
dBHL:	Decibel, Hearing Level
HHS:	Hearing Handicap Scale
HHSS:	Hearing Handicap and Support Scale
HHIE:	Hearing Handicap Inventory for the Elderly
HDV:	Hörsel och dövverksamheten
ICF:	International Classification of Functioning, Disability and Health
ICIDH:	International Classification of Impairment, Disability and Handicap
PTA:	Pure tone average at the 500, 1000 and 2000 Hertz frequencies
ROPP:	Rating of Perceived Participation
SNHL:	Sensorineural Hearing Loss
SPSS:	Statistical Product and Service Solutions (IBM SPSS Statistics)
SRS:	Speech Recognition Score
WHO:	World Health Organization

INTRODUCTION

As you get older, your senses become less acute, and you may have trouble distinguishing details. All senses receive information of some kind from the environment e.g. the eye perceives light and the ear sounds. The ability to hear is critical to the understanding of the world around you and therefore hearing loss may have a tremendous impact on your quality of life and yours lifestyle.

Hearing and aging

Loss of hearing can be categorized by which part of the auditory system that is damaged. There are two basic types of hearing impairments: conductive hearing loss and sensorineural hearing loss (SNHL). SNHL occurs when there is damage to the sensory cells inside the cochlea in the inner ear. Loss of the sensory hair cells in the cochlea constitutes the most common type of permanent hearing loss and in most cases, SNHL is due to aging. Usually, the loss of hair cells starts at the basal turn of the cochlea, where the hair cells responsible for high frequency hearing function are situated. This means loss of the ability to recognize the toneless consonants s, f, t, p, h and k and also sound like sj, tj and sch. In particular, this reduces the ability to recognize speech in noisy environments or in conversations between several speakers (1). SNHL can affect your life also in many other ways. Your social interactions may be reduced as you miss out on conversations with friends and family. On the telephone, you may find it hard to hear what the caller is saying. Sometimes hearing problems can make you feel embarrassed, upset, or lonely as it is easy to withdraw when you can’t follow a conversation at the dinner table or in a restaurant. Unfortunately, SNHL cannot be medically or surgically corrected (2).

The handicap concept - a relic from the period between 1600 - to 1900's

Since the 17th century, handicap has been used in different competitions, in which the chances of the competitors are sought to be equalized by giving an advantage to the less efficient or imposing a disadvantage upon the more efficient. From having had a positive meaning for the weaker party, in the 20th century the term was used to characterize the physical or mental limitations and consequences that affect individuals with a disability (3). So did the *World Health Organization* (WHO) in its classification *International Classification of Impairment, Disability and Handicap* (ICIDH, 1980) (4), which provided a unifying framework for classifying the consequences of disease. Today, the ICIDH is almost 35 years old. Many people have felt uncomfortable by the handicap concept as persons with a handicap were being regarded as inferior or less able compared to others. Therefore, the approach which had been employed to date for dealing with and classifying those aspects related to handicap have been revised and updated by the WHO. In 2001, in order to increase the understanding of people's engagement in their own lives, the term "handicap" as used by the ICIDH has been redefined by the recent classification *International Classification of Functioning, Disability and Health* (ICF) in terms of participation (4) .The upgrade from ICIDH to ICF has been aimed at reflecting the wish to replace negative perspectives of impairments, disabilities and handicaps for a more neutral view of functioning, considering positive perspectives of activities and of participation (5).

International Classification of Functioning, Disability and Health (ICF, 2001; *svensk översättning: Klassifikation av funktionstillstånd, funktionhinder och hälsa*)

ICF provides a framework for coding a wide range of information about health, classification of health and health-related domains. These domains are classified from body, individual and social perspectives; moreover ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction. All aspects of a person's life (development, participation, and environment) are incorporated into the ICF instead of solely focusing on his or her medical diagnosis. Diagnoses are important for defining the cause and prognosis a medical condition, but reveal little about one's functional abilities. Identifying the limitations of functioning is often the information needed to plan and implement rehabilitative interventions.

ICF is a model of functioning and disability that allows for examination of the consequences of a disease or disorder in three dimensions: 1) body function and body structure (symptoms and impairments), 2) activities and 3) participation. To describe and understand a person's health situation, ICF originates from different terms (figure 1).

- <u>Health condition</u> is an umbrella term for a disease, disorder, injury or trauma, i.e. the problems/symptoms for which a person seeks medical care or for the diagnosis of that person.

- <u>Anatomical structure</u> refers to the various body parts, organs, limbs and their components, while

- <u>Body function</u> relates to psychological and physiological functions.

- <u>Activity</u> is aimed at describing how a person carries out various tasks or actions.

- <u>Participation</u> refers to a person's involvement in their lives e.g. to perform tasks at work or in private life, to communicate, to receive messages, to be someone's social support or to learn. Participation also includes problem solving, interpersonal interactions and relationships within or outside the family, social community, social and civic life, leisure activities, religion, and many other situations.

- <u>Environmental factors</u> include the physical, social and attitudinal environment in which people live and work. This includes products and technology for everyday use in homes and at work, natural and environmental factors such as lighting and sounds; personal support and relationships with the closest family, relatives, friends, colleagues, people in positions of power; attitudes of family, friends, of professionals, the wider community; social norms; facilities, services, systems and policies concerning work, employment, education, health care, in social security, etc.

- <u>Personal factors</u> are the personal background of a person's life and times, as well as various personal characteristics such as gender, age, lifestyle, habits, and choice of coping strategies, social background, education, and more.

In general, rehabilitation interventions aim at improving the “Activities and Participation” part in the ICF, which in turn is divided into 9 domains:

- Learning and applying knowledge (domain/chapter 1)
- General tasks and demands (domain/chapter 2)
- Communication (domain/chapter 3)
- Mobility (domain/chapter 4)
- Self care (domain/chapter 5)
- Domestic life (domain/chapter 6)
- Interpersonal interactions and relationships (domain/chapter 7)
- Major life areas (domain/chapter 8)
- Community, social and civic life (domain/chapter 9).

Activity limitations and participation restrictions due to hearing loss are included in at least four out of the nine ICF domains being the communication domain (chapter 3), the interpersonal interactions and relationships domain (chapter 7), the major life areas domain (chapter 8) and the community, social and civic life domain (chapter 9). When planning for the audiological rehabilitation program all four domains need to be addressed by the audiologist performing the training and hearing aid fitting. For a successful rehabilitation, it is important that the individual patient’s specific wishes, needs and circumstances are investigated and put in focus and that the rehabilitation is carried out in cooperation with the patient and also together with the significant other. With the help of ICF, increased possibilities are at hand for developing such an audiological rehabilitation model, aimed at increasing participation and life satisfaction in people with hearing loss.

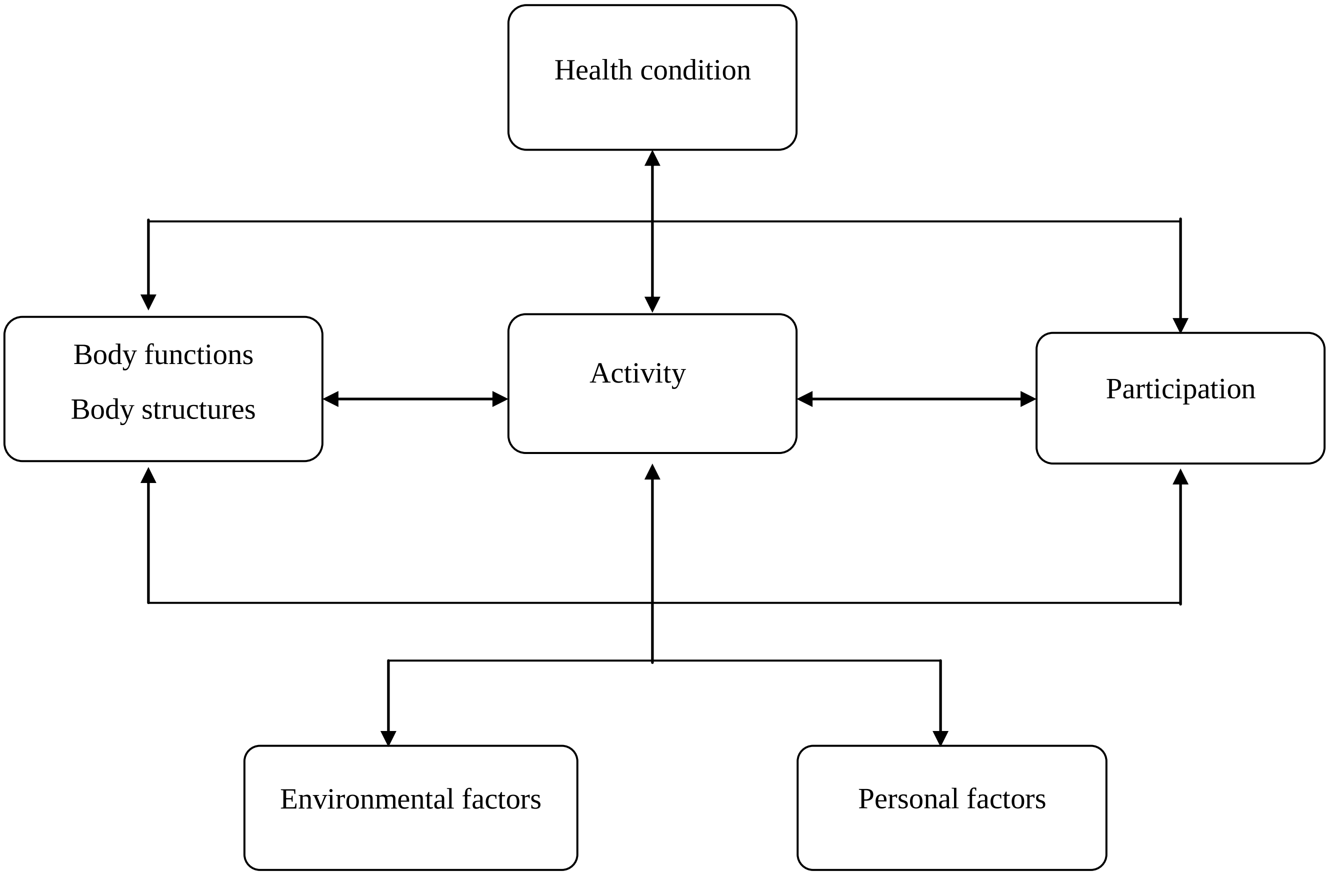


Figure 1. General model of ICF, displaying the interaction between the ICF's various parts, as well as the role of environmental and personal factors. The different parts interact with the person and determine the opportunities/barriers to an activity or participation in that activity. Through this interaction different efforts made can affect one or several areas.

ICF's structure in general, and from an auditory perspective

One aim of the ICF is to create a systematic coding scheme for health information, which identifies how much the operational state is limited in a person without assisting tools. A person's health or health-related condition can be classified by selecting the most accurate code in the ICF.

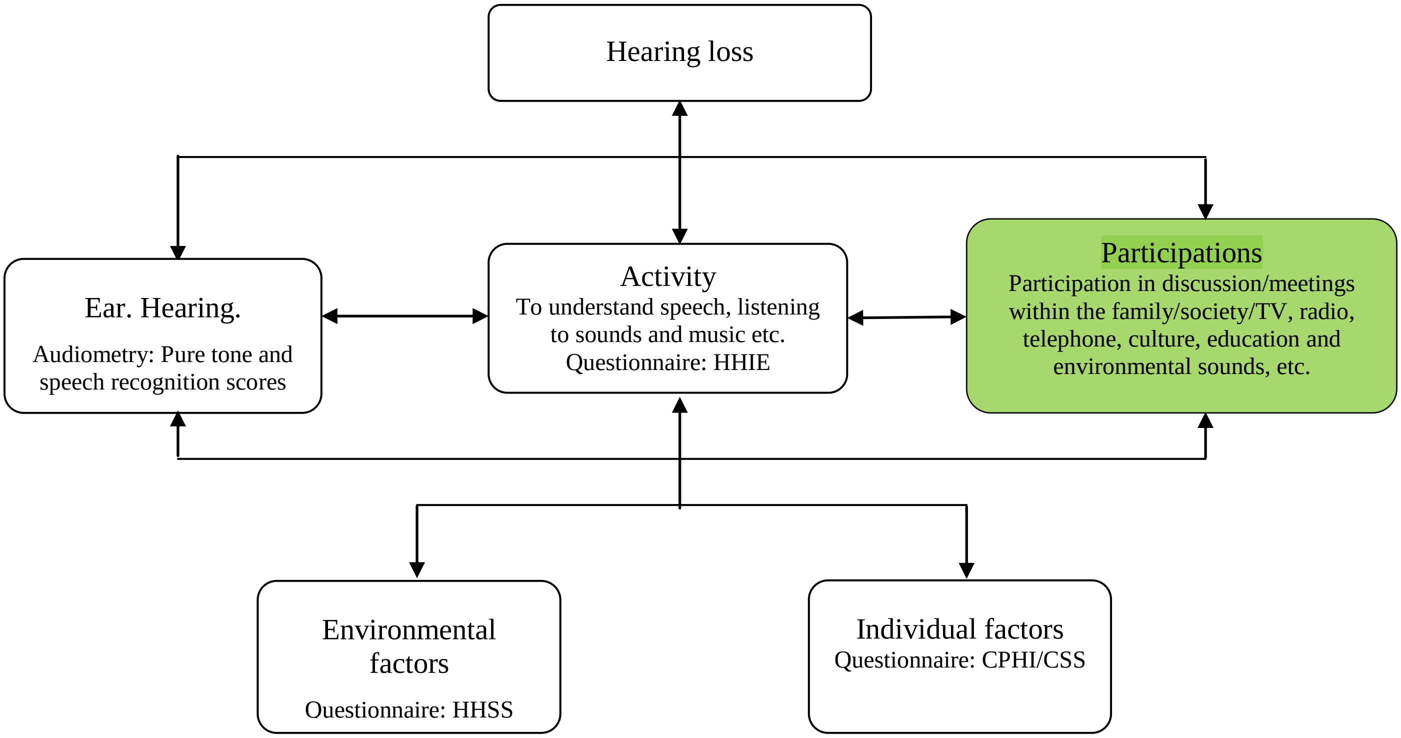
The ICF has two parts: Part 1 covers Functioning and Disability and includes the components: *Body Functions* (eight b codes) and *Body Structure* (eight s codes) and *Activities and Participation* (nine d codes). Part 2 covers *Contextual Factors* and includes the components: *Environmental Factors* (five e codes) and *Personal Factors* (not yet completed). In the ICF classification, the letters b, s, d and e (referring to the corresponding component of the classification) are followed by a numeric code that starts with that chapter number (a single digit, first ICF level) followed by the second level (two digits) and the third and fourth level. One item can be linked to one or more ICF codes depending on the number of concepts contained in that item (6). See table 1.

Table 1: Examples of ICF components, ICF codes and ICF categories relating to hearing.

ICF-component	ICF-code	ICF-category
Body function	B230	Hearing
Body structure	S260	Inner ear
Activities and participation	D310	Communication
Environmental factors	E125	Technology for communication

Hearing, audiological rehabilitation and ICF

In audiological practice, psychometric measuring instruments (questionnaires) have been used for more than fifty years, i.e. even before the ICIDH was endorsed. So far, a number of ICIDH-based questionnaires with moderate validity and reliability have been introduced and used worldwide in audiological rehabilitation services (7). When adapting the general ICF model in figure 1 on hearing function focusing on “Participation in hearing demanding situations”, the ICF can be used as basis for an auditory rehabilitation model (figure 2) as to measure the function in the auditory system, where internationally standardized pure tone audiometry and speech audiometry testing are the gold standards worldwide. Activity is assessed by the current questionnaires for disability, despite being ICIDH-based. Out of the individual factors, coping skills can be estimated using the subscale “Communication Strategy Scale” from the “Communication Profile for the Hearing Impaired”. Among the environmental factors, the “Hearing Handicap and Support Scale” can be used to assess social support and attitudes from others. For the participation box however, there is to this date no questionnaire available.



Figur 2. ICF based on participation in auditory demanding situations for person with hearing loss.

PURPOSE

In auditory rehabilitation, there is a need for accurate clinical instruments that measure the patient’s perceived level of participation and also to direct the rehabilitation interventions according to the patient’s explicit desire to change a particular domain of the ICF. The purpose of this thesis was to study the prerequisites for designing a questionnaire that fulfils these requirements.

SPECIFIC AIMS

The first specific aim was to conduct a literature review in order to find scientific procedures of how to construct and validate on new psychometric instrument to assess restriction in participation as defined by the ICF.

The second specific aim was to construct a new instrument assessing hearing problems in auditory demanding situation as experienced by elderly persons with presbycusis who are referred for Auditory Rehabilitation

The third specific aim was to conduct a pilot study in order to validate the new questionnaire.

STUDY I:
LITERATURE REVIEW

BACKGROUND

To identify studies on similar issues, a literature review was performed. In a first step, studies of interest were reviewed at abstract level. Articles selected were then reviewed in detail for exclusion due to quality criteria. Finally, procedures for data extraction followed and also tabulation of studies that meet our requirements.

MATERIAL AND METHODS

Search strategy

The literature search was done in the electronic database PubMed using the following search terms and limitations (human; age limits 45+: publications from 2002-01-01 and onwards; table 2).The search term ”psychometrics” identified 12345 hits, the term “questionnaire” 63008 hits and “hearing” gave 9317 hits. For the combination of these three search terms, 24 publications were found. However, when ”international classification of functioning” was included as a fourth search term, then no publications were identified. Therefore priority was given to the three most general terms, i.e. the ”hearing” term was excluded. In the final search, which included “psychometrics and questionnaire and international classification of functioning”, 21 publications emerged.

Selection of seven abstracts fulfilling the inclusion criteria

In the search ”Psychometrics and questionnaire and ICF”, 21 abstracts were identified out of which 7 used ”rehabilitation” as key word. These 7 publications were selected for the final review of the whole original article. However, one abstract concerned an assessment instrument to be filled in by the physician and not by the patient. Accordingly, and also because this was not a self-administered questionnaire, that abstract was excluded (8). One the other hand, in another abstract, the potential utility of a questionnaire was determined in a population of individuals with age-related sensorineural hearing loss (9). Since that abstract had a follow up study to test that questionnaire's responsiveness to hearing aid interventions, both abstracts were included (9,10). The main aim of all the 7 original articles selected was to construct and evaluate a new psychometric instrument based on the ICF concept, domains and definitions.

Table 2. The literature search strategy in PubMed. Limits: Humans, Middle Aged + Aged: 45+ years, Publication Date from 2002/01/01.

Search	**Query**	**Items found**
#18	Search **psychometrics AND questionnaires AND international classification of functioning**	21
#17	Search **psychometrics AND questionnaires AND hearing AND international classification of functioning**	1
#16	Search **(#10) AND #9 AND international classification of functioning**	0
#11	Search **(#10) AND #9**	24
#10	Search **(#7) AND #8**	3509
#9	Search **"hearing"**	9317
#8	Search **"questionnaire"**	63008
#7	Search **"psychometrics"**	12345

RESULTS

Full review on article level

In total, seven publications were selected for full review, as follows below.

1. Development and evaluation of a new questionnaire for rating perceived participation.

Marianne Sandström and Lillemor Lundin-Olsson.

***Clinical Rehabilitation* 2007; *21; 833-845,* (10).**

Instrument development, construction and design

The original generic questionnaire “Rating of Perceived Participation” (ROPP) was developed for people with chronic neurological disease. ROPP was initially derived from items selected from the*” International Classifications of Functioning and Disability, beta-2 draft”* (4), but was later changed and structured in accordance with all nine ICF domains. Several Swedish expert panels reviewed the preliminary version of ROPP for content validity, purposes, relevance, comprehensibility and clarity.

Outcome measures, response format and scoring

In ROPP, four outcome variables are presented to the patient, as listed below:

1. Restriction concerning perceived level of participation, i.e. the extent to which full participation is accomplished as “making decisions on one's own and acting of one's own accord” or “being able to act as one wish”. These questions have a five-point scale ranging from

    0 = not restricted
    1 = mildly restricted
    2 = moderately restricted
    3 = very restricted
    4 = severely restricted

2. Patient’s satisfaction with the current level of participation (yes/no).
3. Patient’s desire for support in changing that level (yes/no).

4. Patient’s selection of the three most important domains for which a change in participation is desired.

The maximum possible sum score is 88; the higher the sum score, the more restricted.

Authors' own evaluation for reproducibility, reliability, and validity of their study

In total, 69 patients filled in all 22 items regarding perceived participation twice. The ROPP showed sufficient psychometric reproducibility, reliability and validity. The Cronbach α for the total score was high. The content validity and clinical utility were regarded as good.

Current evaluation for the present

Benefits:

1. The study focused on “participation”
2. The patients have the opportunity to answer questions about their own perceived level of participation in different life situations and also their own level of satisfaction with that participation. Furthermore, the patients can also assign their own priority to the domain in which they most want a change to occur. The patients’ own judgements take precedence over those of the professionals, thereby increasing the patients’ influence on their rehabilitation. Each professional can proceed further in the rehabilitation process by performing specific assessments directed towards the domains prioritized by the patient or to assess short or long term outcomes.

2. Development and Initial Psychometric Evaluation of the Participation Measure for Post-Acute Care (PM-PAC).

Gandek B, Sinclair SJ, Jette AM, Ware JE Jr.

American Journal of Physical Medicine and Rehabilitation 2007; 86:57–71, (11).

The PM-PAC is a generic instrument which measures the extent to which the person was or felt limited in a life situation. In this study, participation reflected "involvement in a life situation", whereas participation restrictions indicated "problems an individual may experience in involvement in life situations". More than twelve different response formats are used to answer the 51 questions.

Instrument development, construction and design

After having conducted a major literature search that included several electronic databases as well as web pages and comprehensive volumes of health questionnaires, the researchers had initially selected a total of 562 items of which 17 items was rewritten. Moreover, to cover all relevant domains of the ICF, 34 new items were designed for situations that were not addressed by the existing items chosen. Items were tested for content validity and modified according to comments from an expert panel and also from individuals with different disabilities. Its final version consists of 51 items, which all are defined by its ICF code. PM-PAC covers six out of the nine ICF domains:

1. Mobility	5 items	ICF chapter 4
2. Major of life areas		
Role functioning	4 items	ICF chapter 8
Economic life	3 items	ICF chapter 8
3. Community, social and civic life	12 items	ICF chapter 9
4. Domestic life	3 items	ICF chapter 6
5. Interpersonal relationships	3 items	ICF chapter 7
6. Communication	3 items	ICF chapter 3

There is also one open question asking the patient whether the PM-PAC survey has asked about all of the important areas in that person's life. The patient is also given the opportunity to add any area that has not been addressed in the questionnaire.

Outcome measures, response format and scoring

The PM-PAC was designed to measure participation outcomes of rehabilitation services provided in outpatient or home-care settings. Most PM-PAC items ask respondents to rate the extent to which they are currently limited in a specific life situation, using twelve different response formats, of which a five-category response scale is the mist currently used as listed below:

1. Not at all, a little, some, quite a lot, completely (item 1)
2. Not at all limited, a little, somewhat, very much, extremely limited (items 2, 7, 9, 16)
3. All of the time, most of the time, some of the time, a little of the time, none of the time (items 3, 5)
4. Every day, 5–6 days, 3–4 days, 1–2 days, never (item 4)
5. Working full-time for an employer, a workshop, or yourself; Working part-time for an employer, a workshop, or yourself; Unemployed but looking for work; Unemployed and not looking for work; A homemaker; Doing full or part-time volunteer service; A full-time student, employment trainee, or in vocational rehabilitation; Retired; Temporarily unable to work because of a disability or health condition; Completely unable to work because of a disability or health condition (item 6)
6. Yes; No, but I would like to be; No, and I do not want to be (item 8)
7. Not at all limited, a little, somewhat, very much, extremely limited, do not do this/not applicable (item 10)
8. I do not have any difficulty doing things socially; I maintain my usual pattern of social activities, despite some difficulties; I am somewhat restricted in the amount or type of social activities I do; I am very restricted in the amount or type of social activities I do; I do not see family or friends, and I only see those who provide care to me (item 11).
9. None, once, twice, three times, more than three times (item 12).

10. Very satisfied, somewhat satisfied, neither satisfied nor dissatisfied, somewhat dissatisfied, very dissatisfied (item 13).
11. None, one, two to four, five to eight, nine or more (items 14, 15)
12. Not at all, a little, somewhat, quite a lot, extremely (item 17).

Details concerning scoring procedures and maximum score values were not reported.

Authors' own evaluation for reproducibility, reliability, and validity of their study

Self-reported data were collected by interview with 395 non-institutionalized rehabilitation patients. Psychometric analyses were sufficient. Test and retest scale scores did not differ significantly. Predictive validity was moderate, and groups with more severe conditions scored worse on the PM-PAC scales. PM-PAC was presented as a promising new measure of patient-reported participation as defined by the ICF.

Current evaluation for the present study

Benefits:

1. PM-PAC used an extensive electronic literature search to identify existing items from questionnaire commonly used for many years in medical practice, which were then adapted to the ICF.
2. PM-PAC was based on clinical experience and knowledge about limitation in participation as perceived by the patients. The authors allowed themselves to design their own questions/items.
3. Allowed construction of new items when necessary to cover the ICF.
4. PM-PAC presents the ICF code.
5. Asking for limitations in participation seems a step forward in the process of designing questions with high accuracy, sensitivity, specificity.
6. For predictive validity purposes, patients were classified according to severity degree of medically assessed impairment and disability (mild/severe). The two groups were then compared regarding the scores when measured psychometrically by the PM-PAC.

Shortcomings:

1. The use of twelve different item scaling formats between questions seems troublesome from a compliance/coherence perspective as the patient may get tired, irritated or even confused.

3. Preliminary Results for the PAR-PRO: A Measure of Home and Community Participation.

Ostir GV, Granger CV, Black T, Roberts P, Burgos L, Martinkewiz P, Ottenbacher KJ. Arch Phys *Med Rehabil 2006; 87:1043-5, (12).*

Instrument development, construction and design

The PAR-PRO is a generic scale and was developed to be used among both disabled as well as nondisabled populations. It was aimed and constructed to complement other assessments, with items designed to cover participation in higher level, more complex life experiences. It was also designed for data collection at three or more points in time, i.e. at admission, discharge, and at points in time following discharge. From reviews, a preliminary list of 50 items was generated from already existing measures and instruments. In an iterative process, the list was analysed for content validity, clearness, suitability etc. by an expert panel, until the list of items was narrowed to 20 items. PAR-PRO represents five of the nine ICF domains being:

1.	Mobility	3 items	(chapter 4)
2.	Domestic Life	6 items	(chapter 6)
3.	Interpersonal Interactions and Relationships	3 items	(chapter 7)
4.	Major Life Areas	4 items	(chapter 8)
5.	Community, social and civic life	4 items	(chapter 9)

Outcome measure, response format and scoring

PAR-PRO reports how often a person's participation in the selected activities is affected. In its first version, the PAR-PRO was presented with a 5 point response format, ranging from 0-4 as follows:

0 =Did not participate in this life situation
1 =Participated monthly (once every 3–4 weeks)
2 =Participated bi-weekly (once every 2 weeks)
3 =Participated weekly (1–4 days per week)
4 =Participated daily/almost daily (5 or more days per week)

From the separate item responses, both a total participation score and a mean participation score was calculated. Low values are consistent with a low participation capacity. However, due to a low response rate in the pilot study, the scaling format was later modified into a scaling system with 3 levels only:

0 = none (activity did not occur)
1 = monthly (activity occurred at least once per month but less than weekly)
2 = weekly (activity occurred at least once per week).

Authors' own evaluation for reproducibility, reliability and validity of their study

A pilot test was conducted on 594 patients with mixed impairments admitted for inpatient rehabilitation by taking part in face-to-face interviews, where the PAR-PRO was filled in by the rehabilitation staff. PAR-PRO was found suitable mainly for people with moderate to severe disability. The instrument showed good internal consistency. The PAR-PRO total participation score correlated inversely with age, but did not differ by sex. Authors concluded that the 20-item PAR-PRO instrument of home and community participation displayed good psychometric characteristics.

Current evaluation for the present study

Benefits:

1. The PAR-PRO was designed as an instrument for assessing short- and long term outcome of rehabilitation.

2. The PAR-PRO was also designed to assess participation rather than disability or activity.
3. PAR-PRO constitutes a complement to other already existing questionnaires.
4. The PAR-PRO offers a separate section with 9 items on patient's satisfaction at discharge and at follow-up.

Shortcomings:

1. The PAR-PRO scaling system using frequency of a situation to occur (“how often”) appeared to be too unspecific and therefore to have a too poor discrimination ability to assess hearing problems, which occur every day.
2. Another short coming was that PAR-PRO regards communication as an activity and not a matter of participation, and was therefore not included on PAR-PRO.
3. The PAR-PRO requires an interview setting as the items are designed as very short statements. For a self-administered questionnaire, full sentences are the option of choice.

4. An outcome measure for Japanese people with knee osteoarthritis, JKOM.

Masami Akai, Tokuhide Doi, Keiji Fujino, Tsutomu Iwaya, Hisashi Kurosawa and Teruo Nasu.

Journal of Rheumatology 2005; 32;1524-1532, (13).

Instrument development, construction and design

The JKOM is a self-administered, disease-specific measure with 25-items, which include patient pain in level walking, standing or climbing stairs; physical functions related to the activities of daily living; and social functions including participation. JKOM is partly referred to the Japanese

Orthopaedic Association Knee Scoring System. New questions to identify disability and impairment were constructed as well. To check content validity, an expert panel was asked for advice. JKOM includes several of the nine ICF domain with emphasis on the mobility, self-care and domestic life domains. However, in its final version, the following subscales are defined:

1. Degree of knee pain	1 item
2. Pain and stiffness in knees	8 items
3. Condition in daily life	10 items
4. General activities	5 items
5. Health Conditions	2 items

Outcome measure, response format and scoring

The outcome measures were designed to incorporate the concepts of the World Health Organization; 2001, and to reflect the specific Japanese cultural lifestyle, which differs from Western countries.

The question concerning the degree of knee pain experienced during the last few days was designed as a Visual Analogue Scale ranging from the far left side or “no pain at all” to the far right or “the most severe pain you’ve ever had”.

The questions regarding knee function were designed to assess the degree of stiffness/pain using a 4 response format: Not at all, slight, moderate, quite extreme.

The wording for most of the ten questions regarding the ability to perform daily routines during the last few days was: “*How difficult is ……?*” Replies were given on a 5 point response scale with options Not at all, a little, moderately, quit, extremely.

Questions the General Activities section and the two Health Conditions items had different wordings and used different response alternatives.

As summery variable, a method calculating the Area Under the Curve was used. High scores are linked to problems/difficulties.

Authors' own evaluation for reproducibility, reliability, and validity of their study
150 patients suffering from knee osteoarthritis participated in the pilot study by completing the JKOM questionnaire and also The Western Ontario and McMaster Universities Arthritis Index (WOMAC), and The Medical Outcomes Study 36-Item Short-Form Health Survey (SF- 36) assessing QOL. JKOM showed sufficient reliability and validity by means of statistical evaluation and comparison with total score in the SF-36 and WOMAC. Test and retest-reliability, internal consistency, content validity, convergent validity, and criterion-related validity were good. Predictive validity was moderate when tested using correlation analysis between pain (VAS scale) and JKOM.

Current evaluation for the present study:
Benefits:

1. Questions are not difficult nor complicated to understand
2. Moderate number of questions

Shortcomings:

1. Questions in the first draft were constructed to identify disability and impairment and not participation.
2. The JKOM scaling system, measuring the frequency of a situation, appeared to be too unspecific, i.e. the level of pain that the participants experienced when performing different activities) and therefore to have a too poor discrimination ability to assess hearing problems, which occur every day.

5. Mobility Activities Measurement for Outpatient Rehabilitation Settings. (MAM). Medina-Mirapeix F, Navarro-Pujalte E, Escolar-Reina P, Montilla-Herrador J, Valera-Garrido JF, Collins SM. Mobility activities measurement for outpatient rehabilitation settings.
Arch Phys Med Rehabil 2011; 92:632-9, (14) .

Instrument development, construction and design
MAM is a disease specific questionnaire for patients with musculoskeletal problems. Items were constructed mainly in three different ways. To identify item candidates from patient-oriented instruments already in use, an electronic database search was conducted. The items selected were linked to the most precise ICF category of the mobility activities domain. Moreover, a subset of items from the original database was then rewritten. Finally, to cover ICF categories not addressed by existing items, some new items were designed as well, in total 51 items had been preselected. Items were reviewed by an expert panel and rated for usefulness, content, clarity, and appropriateness for patients with musculoskeletal conditions. The final version of the 22-item disease-specific Mobility Activities Measure was solicited from different professionals in the rehabilitation field.

Outcome measure, response format and scoring
MAM assesses limitations in daily activities across major ICF categories of the mobility domain, using a 5 point Likert scale with options ranging from “able to do without any difficulty” to “unable to do”. All items in a questionnaire included an overall question that was phrased, “How much difficulty do you currently have (without help from another person or device) with the following activities?” No summery variable was reported.

Authors' own evaluation for reproducibility, reliability, and validity of their study
In a pilot study, 615 patients with musculoskeletal diseases participated, who were receiving rehabilitation services at outpatient rehabilitation settings in Spain. Exploratory factor analysis was used to evaluate the MAM showing satisfactory validity.

Current evaluation for the present study

Benefits

1. The questionnaire had new questions which were specifically written to cover the corresponding ICF code.

Shortcomings

1. Questions were aimed to asses limitation in daily activities, but the phrasing of most items reveal that that MAM measures disability as defined by the ICIDH from 1988 (“How much difficulty do you currently have (without help from another person or device) and not limitations in participation according to ICF.

6. The WHO-DAS II: Psychometric Properties in the Measurement of Functional Health Status in Adults With Acquired Hearing Loss.

Theresa H. Chisolm, Harvey B. Abrams, Rachel McArdle, Richard H. Wilson and Patrick J. Doyle.

***Trends in amplification 2005;9: 111-126,* (9).**

and

7. The WHO-DAS II: Measuring Outcomes of Hearing Aid Intervention for Adults.

Rachel McArdle, Theresa H. Chisolm, Harvey B. Abrams, Richard H. Wilson and Patrick J. Doyle.

Trends in amplification 2005 9: 127-142, (15).

Instrument development, construction and design

The WHO developed the Disability Assessment Schedule II (9), (4), a generic instrument grounded in the WHO’s framework for the ICF. In these two studies, no WHO-DAS II item was rewritten and no new items designed. Here WHO-DAS II was used to assess difficulties with functioning and disability due to hearing loss over the past 30 days. Its psychometric properties were investigated to determine the responsiveness of the WHO-DAS II communication and participation domains, and the total score to hearing aid intervention.

Outcome measure, response format and scoring

Each of the 38 items ask “In the last 30 days how much difficulty they have. The WHO-DAS II includes items in the domain of communication, with two of the items appearing to be particularly relevant to individuals with hearing loss. They asked ”how much difficulty a person has with generally understanding what people say” and ”about difficulty with starting and maintaining conversations.”

Responses are given on a 5- point Likert-type scale from 1 (none) to 5 (extreme/ cannot do). If patients report having problems, patient is also fill in a second question: How much did these difficulties interfere with your life?

None – mild – moderate – Severe – extreme, raw scores are transformed into standardized scores, with 0 indicating the highest level of functioning and 100 indicating the lowest level of functioning or with 0 indicating the best health state and 100 indicating the poorest health state. In this study the following ICF domains were represented:

Activity domains (related to tasks and interactions by an individual):

(1) Communication (*i.e.*, understanding and communicating with the world)
(2) Mobility (*i.e.*, moving and getting around)
(3) Self-care (*i.e.*, attending to one's hygiene, dressing, eating, and staying alone)

Participation domains (involvement in life situations):

(4) Interpersonal (*i.e.*, getting along with people)
(5) Life activities (*i.e.*, domestic responsibilities, leisure, and work)
(6) Participation in society (*i.e.*, joining in community activities)

Authors' own evaluation for reproducibility, reliability, and validity of their study

The study group included 384 veterans with adult-onset mild, high frequency sensorineural hearing loss and no prior hearing aid experience. The participants were randomized into an immediate treatment (IT, 189 participants) group for the larger project examining the effects of hearing aid intervention on quality of life and the other half to a delayed treatment (DT group, 191 participants). WHO-DAS II showed moderate correlations with Abbreviated Profile of Hearing Aid Fitting Benefit (APHAB), the Hearing Handicap Inventory for the Elderly (HHIE) and the Short Form-36 for veterans (SF-36V). Internal-consistency reliability for communication and participation was high concerning Cronbach α, as were test-retest reliability. The WHO-DAS II communication domain and total scores, but not the participation domain, were sufficiently responsive to hearing aid intervention. The APHAB and HHIE, both disease-specific measures, were more sensitive to hearing aid intervention than the generic measure.

Current evaluation for the present study

Benefits

1. Divided into different sections which are related to communication.
2. Assessed how much the hearing aid changed the Quality of Life
3. The aims is equal to the aim in this study
4. Patients had sensorineural hearing loss and had not used hearing aids before
5. Relevant to compare with APHAB and HHIE

Shortcomings

1. Too many items that were not relevant for this group of patients
2. WHO-DAS II is difficult to understand and to fill in
3. Results are difficult to present since 0 indicate best of health and 100 poorest of health (should be the other way around)
4. The WHO-DAS II did not have the same sensitivity and accuracy as APHAB to assess the outcome of hearing aid fitting.

DISCUSSION

A main finding from this literature review was that no previous ICF-based questionnaire on hearing could be identified in PubMed. Accordingly, DHS is the first. There was however the WHO designed generic instrument WHO DAS II, that had been tested on hearing aid intervention, but turned down due to a too poor sensitivity and accuracy to detect sufficient change concerning outcome after audiological rehabilitation compared to the disease specific Abbreviated Profile of Hearing Aid Fitting Benefit (APHAB). Accordingly, DHS was decided to be disease-specific and not generic.

Table 3. Summary for all studies included in the review. S: Suitable. N: Not suitable.

Questionnaire	Country of origin	Instrument construction	Outcome measure	Item design	Item scaling characteristic	Evaluation
ROPP	Sweden	S	S	S	S	S
PM-PAC	USA	S	S	N	N	S
PAR-PRO	USA	S	N	N	N	S
JKOM	Japan	S	S	N	N	S
MAM	Spain	S	N	N	N	N
WHO DAS II	England	N	N	N	S	S

When scrutinizing the way the different research groups had planned for the construction of their coming questionnaire, it immediately became obvious that all groups recycled relevant already validated items as basis (table 3 and 4). They also allowed themselves to modify items if necessary to fit the ICF, and to design a small number of new items to cover new situations as defined by the ICF. The situations commonly described as problematic by patients with hearing impairment are well recognized and formulated in different questionnaires that have been used in audiological practice for many years to gather information regarding a patient's hearing problems. For DHS, candidate items focusing situations that are defined by the ICF were to be selected from the Hearing Handicap Scale (16), the Social Hearing Handicap Index (17), the Hearing Handicap Inventory for the Elderly (18) and Hearing Measurement Scale (19).

Table 4. Summary of publications. G: Generic. D: Disease specific.

Article	Outcome variable	ICF domains	Other question-naires	Own construct	Internal consistency. Cronbach α	Content validity /experts	Reproduci-bility	Test-retest
1. ROPP. Sandström and Lundin-Olsson (2007)	Self-rated perceived participation. Satisfaction and own choice	9/9	Impact on Participation and Autonomy questionnaire (IPA)	Yes	0.90	Yes	Good in all but one item	High agreement
2. PM-PAC. Gandek et al. (2007)	Limitations, Participation	6/9	Impact on ICF & participation (IRT)	Yes (34 new items)	0.61-0.86	NO	Good	r= 0.61-0.86
3. PAR-PRO. Ostir et al. (2006)	Participation in activities consistent with the ICF domains.	5/9	Functional Independence Measure (FIM)	Yes	0.77	Yes	Good	Not performed
4. JKOM. Masami et al. (2005)	Disability Impairment	3/9	No	Yes	0.911	Yes	Good	Good
5. MAM. Medina et al. (2011)	Limitations Activities	2/9	No	Yes	0.70	Yes	Good	r= 0.68-0.88
6. WHO-DAS II. a) Chisolm et al. (2005) b) McArdle et al. (2005)	Communication Mobility Self-care, Interpersonal life activities Participation	6/9	No items rewritten. No new items designed	Yes	0.68-0.91	No	Good	Good

Several different outcomes measures were used by the different studies and the number of scoring alternatives was large also within one and the same questionnaire. In order to optimize the validity, the compliance of the patient needs to be optimized. Especially among the participants of the present study, who were to be asked to fill in all questionnaires also a second time. Therefore, a single response format to be used throughout all items of the DHS was preferred.

Out of this selection of scientific presentation of how to construct and validate a new questionnaire based on the ICF, as shown in tables 3 and 4, the ROPP was outstanding. Only the ROPP was found suitable on all five parts scrutinized being instrument construction, outcome measures, item design, item scaling characteristic and finally the evaluation procedures. No design better than ROPP could be found, it also had a five step response format. In particular, the ROPP design seemed suitable also from an audiological point of view when assessing participation in auditory demanding situations. It also used the same response format for all questions. The statistical evaluation procedures were almost identical between studies and included standard methods for reproducibility, reliability and validity, which were also performed for the current evaluation.

CONCLUSION FROM LITERATURE REVIEW

ROPP was selected as model for the new questionnaire (10). The final step in this literature study was to contact professors Marianne Sandström and Lillemor Lundin-Olsson, who generously provided an electronic version of ROPP and also a written consent allowing us to use their ROPP design for a new questionnaire on hearing.

STUDY II.

CONSTRUCTION AND EVALUATION OF THE DISEASE-SPECIFIC ICF-BASED QUESTIONNAIRE "PARTICIPATION IN HEARING DEMANDING SITUATIONS"

(*Svensk översättning: Deltagande i Hörselkrävande Situationer, DHS*)

BACKGROUND

To ascertain the effectiveness and usefulness of the questionnaire DHS, and to ensure that all relevant aspects are included, the generation of items was conceived through the outcome of the literature review above, where four main factors emerged:

1. DHS should be a disease-specific and not a generic questionnaire.
2. To assess restriction of participation in auditory demanding situations due to hearing impairment, DHS should be based upon a selection of items from old questionnaires often used in audiological practice worldwide.
3. To cover all ICF codes relating to hearing and communication, there was also a need for designing new items as well.
4. The DHS design should be based "ROPP" by Sandström and Lundin-Olsson (10), which was identified through the literature review.

METHODS

Construction

The new psychometric hearing instrument that is specifically investigated and validated in this study originates from the questionnaire called "*Rating of Perceived Participation*" (ROPP; in Swedish "*Skattning av upplevd delaktighet"*), which was originally developed for persons with chronic neurological damage and based on the ICF (10). The present study resulted in a new questionnaire assessing perceived participation in hearing demanding situations, which was named in Swedish to "*Delaktighet i Hörselkrävande Situationer*" (DHS, Appendix 2).

In the first step when constructing the DHS, the ICF domains relating to communication and hearing were identified from the nine ICF domains (as listed below), out of which four were selected to be included in the DHS, i.e. communication (ICF chapter 3), interpersonal interactions and relationships (ICF chapter 7, major life areas (ICF chapter 8) and community, social and civic life (ICF chapter 9) (for details of subdomains and specific codes, see appendix I). The domains learning and applying knowledge (ICF chapter 1), general tasks and demands (ICF chapter 2), mobility (ICF chapter 4), self-care (ICF chapter 5) and domestic life (ICF chapter 6) were excluded from the DHS.

In the second step, the ICF codes selected in the first step were matched versus the items from the most commonly used questionnaires in audiological practice in Sweden, i.e. mainly the Hearing Handicap Scale (16), the Social Hearing Handicap Index (17), the Hearing Handicap Inventory for the Elderly (18) the Hearing Measurement Scale (19) and its different Swedish versions such as the "Gothenburg Profile" (20). In order to cover ICF situations not considered in the old questionnaires, two new items were designed. Later, as advised by the expert panel, another two new items were constructed (item 23 and 24), in total 4 new items. Origin of the 24 preliminary items is presented in table 5.

Table 5. Origin of the 24 DHS items, their corresponding ICF code for the situation addressed.

DHS item	Origin	ICF-code	ICF situation
1	HMS1, HHS12	d350	Conversation one-to-one
2	SHHI2, SHHI7, HMS2, HHS14B	d350	Group conversations
3	HHIE3, HHS10A	d350	Whispering in your ear
4	SHHI16, HMS2, HHS16A, HHS9	d350	Group conversation at a dinner table
5	HMS3, SHHI20, HHS15A, HHS9	d350	Group conversation at a party
6	SHHI11, HHS5A	d350	Conversation during transportation in a car, bus or train
7	SHHI20, HHIE10, HHS15A	d350	Conversation at a restaurant
8	HHIE6	d910	Participation in community life
9	SHHI5, HHS2A	e125	Conversation using a telephone with a person you do not know
10	SHHI15, HMS7, HHS1B	d360	Listening to TV when the loudness is set by a person with normal hearing
11	HHIE6, HHS17A	d920	Experience cultural event such as theater, opera, cinema
12	SHHI14, HHS7A	e250	Recognizing one's voice without seeing that person
13	HHS20B	e250	Waking up by the sound from an alarm clock
14	HMS15, HHS6A	e255	Recognizing sound direction of traffic noise
15	HHIE2, HHS16A	d760	Maintaining family relationships
16	HHIE5, HHIE9, HHS17A	d750	Maintaining social relationships
17	SHHI8, HHIE6, HHS18A	d930	Religion and spiritual activities
18	HHIE6, HHS17A	d920	Recreation and leisure
19	New	d845	Working life
20	HMS20	d355	Meetings and discussions at work
21	HHIE1	d730, d740	Contact with non-relatives, formal relationships
22	New	d830	Possibility to higher education
23	New	d770	Intimate relationships
24	New	d660	Assisting others

DHS layout including item wordings, response format scoring

In DHS, the definition of “participation” is that of “being able to act as one wishes” (in Swedish: *att man i den utsträckning och på det sätt man önskar kan delta i …)*, (se appendix 2). All the 24 main statements have the same scoring system using a five-point response format (0-4) to score the present level of perceived participation as follows:

0 points = not significantly restricted
1 points = mildly restricted)
2 points = moderately restricted
3 points = very restricted
4 points = severely restricted

The person is asked to estimate his/her perceived participation in the 24 situations by putting a circle around the figure representing the current level in restriction of participation as given above. If the patient responds “not applicable”, then that item is given 0 points and the item is excluded from the total summery score, which will be transformed into a total percentage score. The maximum DHS score is 96 points or 100%, the higher the DHS value, the more restrictive the perceived participation.

The supplementary questions linked to each item concerning satisfaction with involvement (“I am pleased with my participation”), and desire for support to increase degree of participation (“I wish to receive help to improve my participation”) have two response alternatives (yes/no). At the end of the questionnaire, there is a request to rank the three most important situations in which the patient wants to change his or her level of participation to occur.

Four main outcome measures

The DHS has four main outcome measures on the level of each of the 24 items. The first main outcome measures the patient’s perceived level of participation in different auditory demanding situations. The second main outcome states whether the patient is satisfied or not with the level of the present participation as given in that particular situation. The third outcome for every question is whether the patient wishes support in order to change the level of participation or not. The

DHS has also a final summery outcome measure that ranks the three most important situations that the patient wishes the rehabilitation programme to improve.

Drafting, expert review and final revision

DHS is aimed to cover those situations that are the most relevant and applicable to the group for which it is intended, namely elderly people with presbycusis. The language used should be easy to understand, there should be no misunderstanding and no item should be perceived as offensive or negative. The first selection of items and an approximation of face[1] and content validity were performed by an expert panel of five audiologists, one ENT specialist, one audiological physician, one technical audiologist, one hearing psychologist, and one hearing therapist. The ten experts filled in an evaluation questionnaire with seven questions about relevance, clearness and comprehensiveness, easiness to understand and read, formulations, offensiveness on item level (yes or no). Results and comments are given in table 6A and 6B below. In particular, item 10 (listening to TV when the sound is adjusted for a person with normal hearing), item 16 (having contact with friends and associates) were those items most criticized by the experts, who didn’t consider the items to be relevant, nor easy to understand or clear and comprehensive. These items were also viewed as easy to misunderstand. Items 9 (Can you talk on the telephone or mobile with a person you don’t know when there is a quite background) and item 15 (having contact with family or close relatives) were commented on, as were item 17 (participating in religious or spiritual activities), item 20 (participating in meetings and discussions on the job), for details see table 6B. The preliminary version consisted of 22 questions before DHS had been reviewed by the expert panel. After having scrutinized the comments and to meet ICF requirements, it was decided that two more questions should be added to the questionnaire, i.e. item 23 (close relationship to the person you are living with) and item 24 (assisting others).

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[1] Face validity is an estimate of whether a test appears to measure a certain criterion; it does not guarantee that the test actually measures phenomena in that domain. Face validity is very closely related to content validity. While content validity depends on a theoretical basis for assuming if a test is assessing all domains of a certain criterion, face validity relates to whether a test appears to be a good measure or not. This judgment is made on the "face" of the test, thus it can also be judged by the amateur.

Table 6. Expert panel review (results are given as a percentage of the ten experts' response). Red boxes indicate items not approved. All 22 items regard conversation, except item 13 (being awakened by the alarm clock).

Item	Relevant	Clear and Comprehens-ive	Easy to understand	Easy to read	Malformed	Offensive	Can be miss-understood
1. One to one	100	80	90	90	10	0	10
2. Group	100	90	90	90	20	0	20
3. Whispering	90	90	90	90	10	0	0
4. Dinner	90	90	80	80	10	0	10
5. Party	100	90	80	90	10	0	10
6. Transportation	100	90	90	90	20	0	0
7. Restaurant	90	80	90	90	10	0	10
8. Community life	90	80	70	80	10	0	20
9. Telephone	90	**50**	60	70	30	0	20
10. TV	80	**50**	**40**	**40**	20	0	10
11. Cultural events	90	80	80	80	10	0	0
12. Voice	90	90	80	80	10	0	0
13. Alarm Clock	80	90	70	70	10	0	10
14.Buss,car, train	90	80	80	80	20	0	10
15. Family	70	60	**40**	70	40	40	**60**
16. Friends	**50**	**30**	**30**	70	40	10	**60**
17. Religious activities	70	60	70	60	20	10	10
18. Hobbies	80	80	80	80	20	0	10
19. Work	70	90	80	80	10	10	0
20. Discussion at work	80	70	60	60	30	0	30
21. Non-relative	70	60	60	60	20	0	10
22. Education	**30**	**50**	60	**50**	20	20	20

Table 7. Comments from the expert panel.

Items	Comments
1. One to one	The question is too complex.
2. Group	Best to delete the words “one of the otherwise quiet environment”
3. Wispering	Good question from a psychological point of view.
4. Dinner	The question can be misunderstood. The question was similar to the question number five. Better to delete item.
5. Party	Two experts thought that there were two different situations in the same item; dinner and party.
6.Transportation	One expert was missing “tram”. There is a great difference between the three different situations: bus, car and train.
7. Restaurant	The question is similar to question number four.
8. Community life	Three experts thought the question is similar to question five.
9. Telephone	It can be difficult to know why one should distinguish between persons you know or do not know
10. TV	The question is complicated. It is enough to include family and friends. Two experts suggested: Remove the word “desired”. Otherwise, it will be difficult to read and it can be misunderstood.
11. Cultural events	There is a big difference between theatre and cinema.
12. Voice	No comments.
13. Alarm Clock	The word “signal” should be replaced by “alarm signal”. One expert did not think it was important to have the alarm clock because there are other ways to wake up.
14. Buss,car and train	No comments
15. Family	The sentence is actually incorrect. It is better to write: ”can maintain relationships with family and relatives“. One expert thought it would be better to use “related” instead of “relatives”. Another expert thought the question was strange because relationship with family and relatives is something probably all have. Two other experts thought the relationship with family and relatives does not need be worse due to hearing loss. Another commented that not everyone has family and relatives. It is best to add “friends”.
16. Friends	Someone thought that the word "informal" and "familiar" should be removed.
17. Religious aktivities	The sentence concerns severe things. It is better to use the word “religious” rather than “spiritual”. It is an unnecessary question and it should be removed. It stands for too many activities in the same issue. One person wondered what ”spiritual” meant. One expert thought that it would be better to use “religious”.
18. Hobbies	All hobbies do not require that you can hear.
19. Work	The word “paid work” was commented on as not everybody is working. The question would be deleted.
20. Discussion at work	The word “relationship” can be interpreted wrongly. It can stand for something else.
21. Non-relatives	No comments.
22. Education	No comments.

PILOT STUDY

Participants

A pilot test was conducted on patients with different degrees of hearing impairment, who had been referred to the Hearing Centre at Västra Frölunda Hospital in Gothenburg, Sweden, for their first hearing aid fitting. All patients had read an information letter and signed a consent before they got questionnaires (Appendix 6, 7). All patients in the rehabilitation group during the period of October 2010 and November 2010 were consecutively selected as eligible participants for the study. The inclusion criteria were persons with different degrees of an audiometric sloping sensorineural hearing loss with characteristics typical for presbycusis ranging from mild to severe and all participants were new hearing aid users. Persons with cognitive impairment or inability to speak Swedish were excluded. A total of 70 persons met the criteria for inclusion. Of these, 6 declined to take part in the study and 14 failed to complete the DHS twice. Of the remaining 50 subjects, 29 were men and 21 women.

Procedures

All patients who came for their first Hearing Centre appointment to have a hearing test were offered to participate in the study (n=70). Patients who signed up to participate in the study filled in the first set of questionnaires during their viset at the clinic. Then then got on envelope to take home (n=64). The envelope contained the four questionnaires DHS, the Hearing Handicap Inventory for the Elderly (HHIE), the Communication Profile for the Hearing Impaired (CPHI), and the Hearing Handicap and Support Scale (HHSS; for details see below) to be filled in at home and returned by mail. Finally, all data from questionnaires and audiometric results were saved in an SPSS sheet for data processing. If the envelopes was not returned, the person was contacted by telephone and reminded to return the questionnaires by mail.

Questionnaires used for validation

For the convergent validity evaluation, three questionnaires often used in Swedish auditory rehabilitation praxis were used

Hearing Handicap and Support Scale (HHSS, Appendix 3)

The HHSS (21) consists of 28 items, which present various claims in 5-point response format ranging from 1-5, “strongly disagree” (1 point), and “strongly agree” (5 points). In this study, HHSS is used to measure the perceived attitudes of the significant others (9 items), and social support from the environment (10 items), while the disability/handicap items were excluded. High scores on attitudes indicate problems. The higher score the larger the hearing problems were 140 and the low score that indicates minor hearing problems were 28.

Hearing Handicap Inventory for the Elderly (HHIE, Appendix 4)

HHIE is a disease-specific instrument for the measurement of health-related quality of life among elderly persons with hearing impairment and the original HHIE consists of 25 items (18). The screening version of HHIE is a ten item questionnaire and is an effective instrument often used to measure emotional and behavioural consequences (5 items) from the hearing loss. All assertions have three response options, where "Yes" is assigned 4 points, "sometimes" 2 points and the "no" is given 0 points (22). The range of total points is from 0-40. 0-8 suggests no hearing handicap, 10-24 suggest mild-moderate hearing handicap and 26-40 suggests significant hearing handicap.

Communication Strategy Scale in the Communication Profile for the Hearing Impaired (CPHI/CSS, Appendix 5)

The communication Strategies Scale of the Communication Profile for the Hearing Impaired, (CSS/CPHI) (23-25) consists of 25 items, assessing how often *maladaptive behaviours* (9 items); *verbal strategies* (8 items) or *nonverbal strategies (8 items)* are used to deal with demanding auditory situations. The patients indicate how often the situation or behaviours occurs, using a five-point response scale ranges between "rarely/almost never" (0 point), "sometimes/every now and then", "every other time", "often", and "usually/almost always" (4 points). Maladaptive behaviours include questions about how often you avoid others finding out that you have hearing problem, for example, by guessing, dominating a conversation or ignoring the person talking. Verbal strategies are used to enhance the effect of a communication, for example, that the hearing impaired person asks for attention before she / he speaks, while the nonverbal strategies aim to facilitate communication without having to ask for help, for example, to sit at the front. Maximum score maladaptive strategies: 36 points; nonverbal strategies: 32 points; verbal strategies: 32 points. High scores for verbal and non-verbal strategies indicate effective coring. For maladaptive strategies, high scores indicate frequent use of maladaptive coping.

Audiometry

For evaluation of predictive validity, hearing assessments for pure tones and words were performance.

Pure tone audiometry

All hearing tests were carried out in a soundproof test room with background sound pressure levels below those recommended by ISO 8253-1. The audiometer (Interacoustics AC-33, Madsen OB-822) were regularly calibrated in accordance with ISO 389 (25). The pure tone average at 0.5, 1, and 2 kHz (PTAmid) and at 3, 4, and 6 kHz (HF-PTA) for both ears were used as statistics.

Speech recognitions scores in noise

The percentage of correct answers out of 50 monosyllabic phonetically balanced words was determined in the presence of a speech weighted noise, low-pass filtered from 1 kHz with a slope of 12dB/octave and with a constants spectrum level from 125 to 1000 Hz (27, 28). The speech-to-noise ratio, as calculated from measurements of the speech and noise levels, was +4 dB. The speech signal was presented at a comfortable level, chosen by the subject, 30-40dB above the speech reception threshold. Both lists used were taken from the ordinary test material commonly used in Swedish speech audiometric practice (2).

Statistical analyses

To define a DHS summery variable, the raw data were transformed and calculated as total scores. This was done by adding the response point for each question into a total sum. To get the final total percentage score, a percentage was calculated between the maximum total sum of the responses and the maximum sum only for those items that the patient had filled in. Items with non-applicable responses were excluded as well. The abbrevation used for this variable in this text was DHS tot%. Statistical analyses were performed using SPSS for Windows version 20 as follows:

Reproducibility and stability (test-retest)

To ensure that the instrument is accurate when measuring the same condition on repeated occasions, a test-retest procedure was conducted. Correlation analysis and t-test was used to estimate the relation between and difference in total DHS tot% at first versus the second test occasion.

Internal consistency (Cronbach´s alpha)

Internal reliability called “Cronbach´s alpha” is a reliability coefficient based on the average covariance among items in a scale and the degree to which items within an instrument correlate to each other. Cronbach's alpha shows how well items measure a single one-dimensional latent construct. The coefficient will generally increase when the correlations between the issues increase. When data have a multidimensional structure, Cronbach's alpha will usually be low. A value of 0.70 was considered acceptable, 0.80 was considered good, and 0.90 was considered excellent (26).

Convergent validity (correlations to questionnaires frequently used in audiological practice)

Shows that the scale is related to what it should theoretically be related to. This was analysed using parametric and Spearman non-parametric correlations between the DHS questionnaire and similar scales in other already validated questionnaires frequently used in audiological practice (HHIE, CPHI/CSS, and HHSS).

Predictive validity (correlations to audiometry)

Predictive validity describes the relationship between audiometric test results and the DHS tot% and is investigated using correlation analyses between DHS tot% and audiometry, in this study mid frequency pure tone average (PTA), high frequency PTA and speech recognition scores in noise. Another method is to use Student’s t-test to determine how well the DHS DHS tot% distinguished between two groups categorized according to the severity of perceived hearing problems (mild/moderate versus substantial/severe), i.e. that the group comprising the study subjects with the low degree scored significantly lower that the group with severe hearing problems.

RESULTS OF THE EVALUATION

Descriptives (table 7)

Perceived Hearing Problems

Most of the women regarded their hearing loss as mild to moderate (29% and 48%, respectively) while most of the men regarded their hearing loss as moderate to substantial (31% and 35%, respectively). Usually, men had had their hearing loss for a longer period of time than women (mean duration: 11 and 7 years, respectively).

Tinnitus

Tinnitus was more common in men than women and occurred often or always among 45% of the men, but only among 15% of the women.

Audiometry

Both pure tone and speech audiometry verified a sensorineural sloping hearing loss, moderated degree for both men and women (figure 4B audiogram). Speech audiometry revealed great inter-individual differences.

Activity

Activity as measured by the HHIE showed a low level of disability and handicap for both sexes and also a narrow range [0-15], meaning that the patients did not have much trouble in situations included in the HHIE.

Participation

Participation showed a low level and also a narrow [0-82 for men and [4-72] for women, that meaning the patient’s has not been involvement.

Environmental factors

The “Hearing Handicap and Support Scale” showed sufficient social support and a low degree of perceived negative attitudes from others.

Personal factors

Data on several personal factors were collected. In general, coping (CPHI) was seldom used by the participants. Most of both men and women lived together with a cohabitation partner. A low education level was more common among men than women, 51% and 34%, respectively. Most participants reported good health.

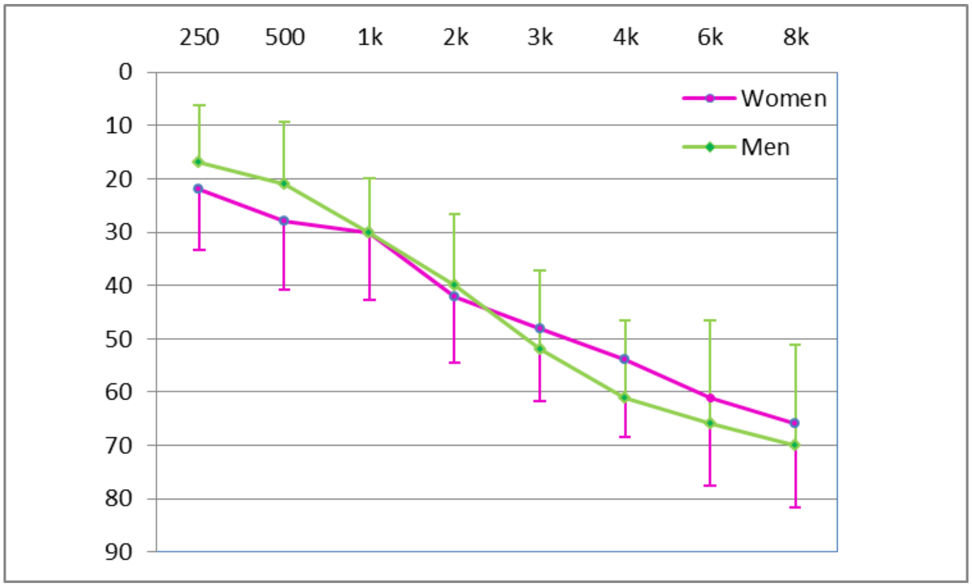

Figure 3. Mean hearing thresholds on pure tone audiometry for men (green) and women (purple). SD is shown as error bars.

Table 7. Participant characteristics (N=50).

Characteristics		
N (%)	29 men	21 women
Hearing loss		
How would you estimate the degree of your hearing problems? N (%)		
Mild hearing loss	8 (28%)	6 (29%)
Moderate hearing loss	9 (31%)	10 (48%)
Substantial hearing loss	10 (35%)	3 (14%)
Severe hearing loss	1 (3%)	1 (5%)
For how long have you experienced hearing problems?		
Years (Mean ± SD); [range]	11±10; [1-35]	7 (8); [1-30]
Tinnitus		
Do you have tinnitus? N (%)		
Never	7 (24%)	12(57%)
Infrequently	5 (17%)	2 (10%)
Sometimes	3 (10%)	4 (19%)
Often	2 (7%)	2 (10%)
Always	11 (38%)	1 (5%)
Missing	1 (3%)	1 (5%)
Audiometry (dBHL)		
PTA (dB)	34 (8); [12-49]	35 (11); [18-62]
HF-PTA (dB)	59 (15); [26-90]	54 (14); [32-90]
SRS in noise	44 (24); [0-86]	41 (30); [0-83]
Activity (mean (SD); [range])		
HHIE	9 (4); [0-15]	10 (4); [2-15]
Participation		
DHS tot%	**31 (22); [0-82]**	**26 (20); [4-72]**
Environmental Factors (mean (SD); [range])		
HHSS/social support	26 (6); [11-36]	23 (5); [14-31]
HHSS/attitudes	11 (7); [0-28]	10 (6); [1-27]
Individual factors		
Age (years: mean (SD); [range])	70 (7, 6); [53-83]	69 (9, 1); [49-84]
CPHI/verbal	15 (9); [2-30]	14 (7); [5-28]
CPHI/non-verbal	12 (8); [2-29]	15 (7); [3-24]
CPHI/maladaptive	5 (5); [0-17]	8 (7); [0-25]
Living situation: N (%)		
Married	14 (48%)	8 (38%)
Living with a partner	2 (7%)	4 (19%)
Living alone	12 (41%)	9 (43%)
Missing	1 (4%)	0
Education: N (%)		
Elementary school	15 (51%)	7 (34%)
High school	2 (7%)	4 (19%)
University	9 (31%)	7 (33%)
Missing	3 (11%)	3 (14%)
Are you at good health? N (%)		
Yes	21 (72%)	17 (81%)
No	6 (21%)	4 (19%)
Missing	2 (7%)	0

Participation in Hearing Demanding Situations assessed by the DHS questionnaire

The perceived degree of restrictions of participation in auditory demanding situations as assessed by DHS varied between zero and very high values (0-82%), but there was no ceiling effect (table 7). In table 8, data on the DHS responses regarding perceived participation in the 24 situations are presented for men and women separately. Situations most frequently reported as troublesome were items 2-11 and item 14, in particular 5 and 6 which concerned group conversation at a party or during travelling in a car, bus or train. Also as shown in table 8 above, situations described in item 15-24 constituted any major problems and nobody responded “Not applicable”.

Men exhibited most dissatisfaction with the situations regarding participation in conversation during a party or dinner (item 4 and 5) and wished to improve their participation mainly in these situations and also during visits to a restaurant (items 5 and 7). Women were not satisfied with their level of participation when listening to the TV when the sound is adjusted for normal hearers (item 10) and wished improvement when listening to the TV, during restaurant visits, and in conversation during a party or a dinner (items 10, 7, 5 and 4). We conclude that these questions were the most important.

The three most important situations in which the patients wished an improvement to occur regarding his or her level of participation were group conversation, during a dinner, in conversation during a party, when listening to TV and when experiencing cultural activities such as theater, opera or cinema, i.e. questions 2, 4, 5, 10 and 11.

Table 8. Percentage of situations on item level with different degree of restricted participations reported in DHS for men (♂, n=29) and women (♀, n=21). Pink boxes illustrate problematic situations. Green boxes indicate less problematic situations.

Item	Not restricted (%)		Mildly restricted (%)		Moderately restricted (%)		Very restricted (%)		Severely restricted (%)	
	♂	♀	♂	♀	♂	♀	♂	♀	♂	♀
1. One to one	52	76	**24**	14	**24**	10	0	0	0	0
2. Group	**28**	**48**	**21**	19	**34**	19	17	14	0	0
3. Wispering	**24**	**48**	**31**	19	**21**	9	17	**19**	7	5
4. Dinner	**10**	**43**	**28**	5	17	**24**	**38**	**19**	7	9
5. Party	**14**	**9**	**24**	**29**	17	**24**	**24**	**19**	**21**	**19**
6. Transportation	**14**	**9**	**24**	**24**	17	**38**	**24**	**14**	**21**	14
7. Restaurant	**7**	**19**	**34**	19	17	**29**	**31**	**24**	10	9
8. Community life	**28**	**33**	**24**	**29**	**28**	**29**	14	9	7	0
9. Telephone	**38**	67	**31**	**24**	**24**	9	3	0	3	0
10. TV	**10**	**9**	**21**	19	**34**	**24**	**28**	**29**	7	**19**
11. Cultural events	**28**	**29**	**28**	19	17	**38**	17	9	10	5
12. Voice	52	67	**21**	**24**	14	9	14	0	0	0
13. Alarm Clock	66	67	**21**	**29**	7	0	7	5	0	0
14.Buss,car, train	**45**	**52**	**28**	**33**	10	5	7	0	10	9
15. Family	62	76	**21**	19	14	5	3	0	0	0
16. Friends	69	67	17	14	7	9	7	9	0	0
17. Religious activities	69	86	14	9	14	0	3	5	0	0
18. Hobbies	59	90	**21**	0	**21**	3	0	0	0	5
19. Work	69	95	17	0	10	0	3	0	0	5
20. Discussion at work	66	62	14	19	10	9	7	5	3	5
21. Non-relative	69	76	17	14	7	9	7	0	0	0
22. Education	79	90	10	0	7	0	3	9	0	0
23. Intermate relationship	79	90	10	5	7	0	3	5	0	0
24. Assisting others	56	81	17	9	3	5	3	0	0	5

Table 9. The number of no answers for satisfaction and yes answers for desired support for change. Pink boxes illustrate problematic situations. Green boxes indicate less problematic situations.

Items	I am **not** satisfied with my participation (%)		I want help to increase my participation (%)		I want to increase my participation in situation number	Then in the situation number	Even in situation number	Total
	Men	Women	Men	Women				
1. One to one	24	5	38	14	0	2	1	3
2. Group	52	14	55	29	3	4	2	9
3. Whispering	45	29	52	29	4	0	1	5
4. Dinner	62	38	59	52	4	11	2	17
5. Party	65	43	65	52	3	1	5	9
6. Transportation	35	48	59	48	4	1	1	6
7. Restaurant	59	43	65	52	1	1	1	3
8. Community life	52	14	41	29	0	0	1	1
9. Telephone	24	5	35	5	0	0	1	1
10. TV	59	52	35	52	2	8	7	17
11. Cultural events	52	43	52	43	8	0	1	9
12. Voice	24	14	24	5	0	0	1	1
13. Alarm Clock	17	14	21	10	0	0	0	0
14. Buss,car, train	31	14	7	19	2	0	1	3
15. Family	14	10	24	14	1	2	2	5
16. Friends	17	33	21	29	2	0	0	2
17. Religious aktivities	24	0	24	14	1	0	0	1
18. Hobbies	21	14	21	19	0	1	1	2
19. Work	24	10	17	10	0	1	1	2
20. Discussion at work	17	19	24	19	0	0	1	1
21. Non-relative	21	19	7	19	0	0	0	0
22. Education	21	5	21	5	1	0	0	1
23. Intimate relationship	10	5	14	43	0	1	0	1
24. Assisting others	3	5	7	5	0	0	1	1

Reproducibility and stability (test-retest)

The DHStot% results (mean ± SD) at test and retest was 28,8 ± 20,9 and 31,5 ± 21,5, respectively (table 7). The correlation coefficient for the DHS tot% score between the first test and the retest was 0,771 (p≤0,000) for the parametric and 0,804 (p=≤0,000) for the nonparametric correlation analysis (The difference between the means was 2,7 ±14,4 having a range from-6.8 to 1,4. Student's paired t-test showed a p value of 0,191, i.e. no significant difference between test 1 and 2.

Internal consistency (Cronbach´s alpha)

Internal consistency reliability was measured by Cronbach's alpha coefficient, for which a value of 0.80 was considered good, and 0.90 was considered excellent (26). In this study, the Cronbach's alpha estimated for the total DHS score was good, i.e. 0,87.

Convergent validity

In the present context, convergent validity was examined by determining if DHS scores reflect scores on commonly used disease-specific psychometric instruments for hearing loss, in this case by estimating the correlation coefficient between the total percentage sum of the DHS and the sum for the responses of different variables as assessed by the HHIE, HHSS and CPHI. Correlations between DHS and other questionnaire weremodest and highest correlations were found between DHS and maladaptive coping strategies (0,587** and 0,624**, respectively). Results are presented in tables 10.

Table 10. Correlations between DHS tot% and other questionnaires and versus audiometry.
**$^{)}$ correlation coefficient is significant the 0.01 level (2-tailed). *$^{)}$ correlation coefficient is significant at the 0.05 level. HHIE = Hearing Handicap Inventory for the Elderly (appendix 4);
HHSS = Hearing Handicap Scale (appendix 3); CPHI/CSS = Communication Profile for the Hearing Impaired / Communication Strategi Scale (appendix 5).

Questionnaire	DHS Parametric	DHS Nonparametric
HHIE	0,537**	0,371**
Attitude HHSS	0,482**	0,426**
Social support HHSS	0,395**	0,427**
Maladaptive, CPHI	0,587**	0,624**
Non-verbal, CPHI	0,446**	0,462**
Verbal, CPHI	0,379**	0,373**
PTA(3,4,6)	0,225	0,354*
PTA(0,5, 1, 2)	0,130	0,269
SRS in noise	0,507	0,22

Predictive validity

The nonparametric correlation between DHS tot% and HF-PTA was weak (r = 0,354*), and both parametric and nonparametric correlations between DHS tot%, PTA, speech in noise and the parametric correlation between DHS tot% and HF-PTA were not statistically significant. To further test predictive validity, patients were divided into two groups according to their subjective perception of their hearing loss and means compared using student's t-test. Group 1 comprised persons with a hearing loss perceived as mild or moderate and group 2 substantial or severe hearing loss (mean DHS tot%: 19,8 and 46,9, respectively; p<0,000). See figure 4 and 5.

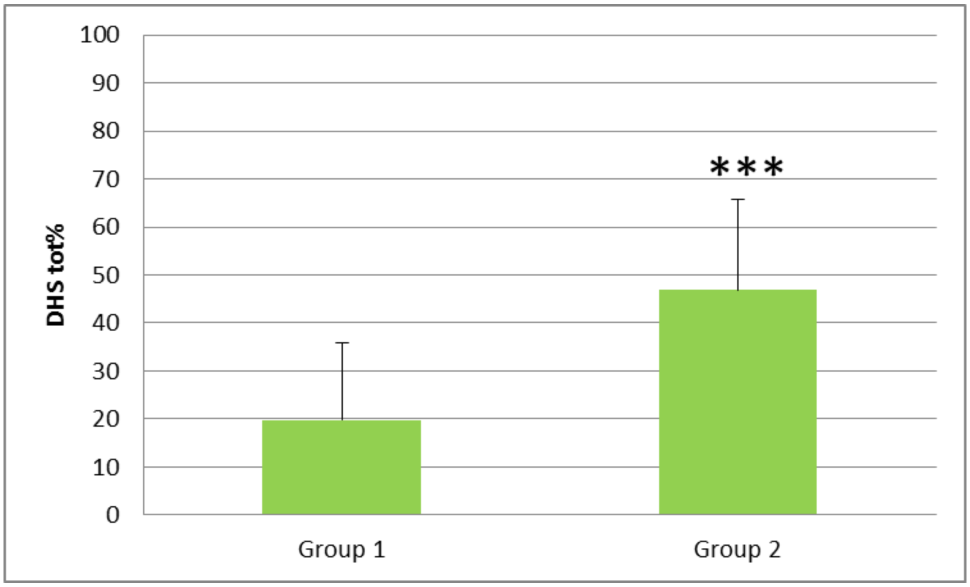

Figure 4. DHS tot% score in patients with mild or moderate perceived hearing problems (group 1) versus substantial or severe hearing loss (group 2). ***) correlation coefficient significant at the P<0,000 level.

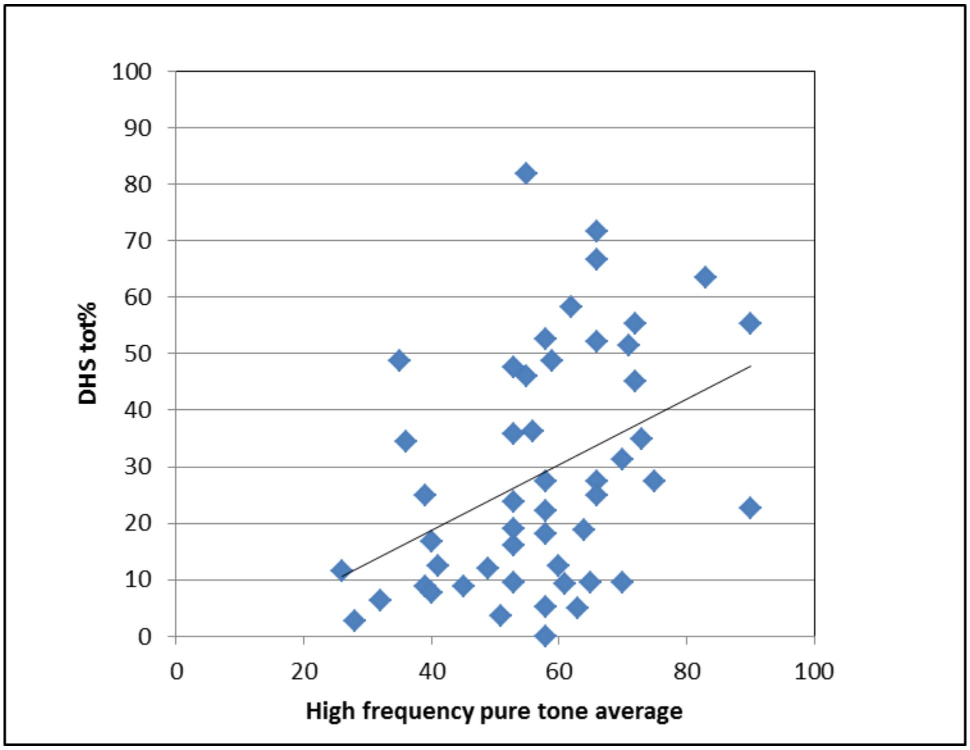

Figure 5. Relationship between DHS tot% score and HF-PTA at the 3, 4, 6 KHz; r=0,354.

GENERAL DISCUSSION

For the first time to our knowledge, a clinical self-rating instrument on hearing that fulfils the requirements of the ICF is being constructed and validated. The DHS measures the patient's perceived level of participation in auditory demanding situations in the context of where he or she lives. It also directs the rehabilitation interventions specifically according to the patient's explicit desire to improve participation in a particular situation. The DHS shows sufficient reliability and validity and therefore, it seems to have the properties of becoming a useful accurate psychometric instrument and to be reliable and valid within a population representing individuals with age-related sensorineural hearing loss. This study indicates that DHS is a useful clinical tool both from the perspective of the patient and also the different audiological rehabilitation professional's point of view.

Constructing the DHS

DHS is a disease-specific instrument, derived from the definitions of perceived participations of the ICF conceptual models as satisfying the criteria for validity. In general, as also shown in previous studies on self-rated hearing questionnaires, disease-specific instruments were found to be more clinically sensitive than generic ones, in particular if assessing intervention outcomes from hearing aid fitting and rehabilitation (9). Moreover, when constructing the DHS, it was decided to follow the same standardized steps as all the studies previously reviewed in study I, i.e. choosing a broad selection of items already in use in audiological practice, which could be defined by a corresponding ICF code. In total, items should be covering the four relevant ICF domains being ***communication*** **(domain 3)*, interpersonal interactions and relationship*** **(domain 7),** ***major life areas*** **(domains 8) and** ***community, social and civic life*** **(domain 9)**. And to design new complementary items for situations that were not addressed by existing items. The origin of each DHS item and its ICF code is presented in table 5, which shows that only four new items were added. However, as can be viewed in both table 8 and 9, those new situations did not have any priority among the current patient group with presbycusis. Instead, as could be expected, the items most often chosen as problematic and troublesome were the same, old ones from the 1960-ies, i.e. communication in noisy environments with significant others including children, grandchildren, other relatives and friends, listening to TV and also cultural activities, a pleasure that should not be forgotten or neglected by the professionals in audiology. These situations were not surprising as they are supported by all previous literature and also audiological clinical practice worldwide.

A clinically useful instrument should be easy for both patients and professionals to understand. It should also be easily administered and quickly completed. Therefore, when constructing this new psychometric instrument, its content validity is of the greatest importance. Since most studies in our literature review had used an expert panel, in which different professionals as well as patients were represented, similar procedures were used also for the current study. The feedback from the present experts was indeed extensive as can be seen in table 6A and 6B, elucidating those items that needed correction of some kind. For example, items 22 and 16. Also another two more new items were added, this was done only to cover two more ICF categories (items 23 “intimate relationships”, d770; and 24 “assisting others”, d660). However, the latter were not considered as relevant by the patients. To summarize, it is satisfactory that many items from the old questions could cover numerous of the ICF categories for communication with other people, especially since this is the most important activity for this age group. Accordingly, the content validity of the DHS is sufficient and thereby satisfactory, since both the four ICF domains regarding communication, and also views from patients as well as all different professionals in Audiology have been taken into account when constructing the DHS.

As postulated by the ICF, the DHS main outcome variables are measuring both degree of perceived participation in auditory demanding situations, as well as whether the patient is satisfied with the current participation and also if the patient wishes to improve his/her participation in that particular situation or not. DHS does not measure how often participation is perceived to be limited as most previous hearing questionnaires do. This was a deliberate choice, since measuring frequency only offers a very simple one-dimensional value that usually is quite non-informative to the audiologist responsible for the rehabilitation plan. The DHS outcome variables on the other hand give information which is multi-dimensional, describing both how much a troublesome hearing situation limits that person´s life (degree) and that that specific hearing situation indeed is something that probably affects that person and his/her surrounding in many different ways, enough to desire and ask for help for an improvement. In turn, this information constitutes the essential basis for the planning of the rehabilitation efforts, which is vital information to the audiologist when conducting the auditory training with the patient and also when evaluating the outcome of the benefit with the hearing aid fitting both in a short- and long-term perspective. In our point of view, the replacement of the concept of handicap with that of participation seems to be an improvement, in particular for the patients, as patients with hearing loss are known to be reluctant to admit their speech recognition problems and their poor and often ineffective coping skills in auditory demanding situations. Hopefully, discussing degree of participation limitations will offer an option less threatening to that person’s self-image than being handicapped. Thereby the accuracy of DHS will be higher than that of questionnaires based on definitions from the old ICIDH classification (disability and handicap).

Evaluating of the DHS

For persons with hearing loss, the requirements from the ICF can be fulfilled by supplying answers not only from the DHS, but also the HHSS and the CPHI. It is therefore advised to use these two questionnaires as well, perhaps already when advising a person to have a hearing aid. All these pieces of information are important to the audiologist when planning for the rehabilitation efforts to come, in particular the possibility to involve the significant other to take part in the rehabilitation process (environmental factor) and also different personal factors (in particular coping skills) as illustrated by the ICF. For the HHIE, there is really no obvious reason any longer for using this questionnaire, but instead to utilize the DHS. This can be seen when comparing its narrow range in the lower part to that of DHS, where almost the whole DHS scale was represented (see table 7: HHIE [0-15] versus DHS [0-82]; Maximum for both scales being 100).

The present study sample is indeed representative for patients in general who come for their first visit to a hearing rehabilitation center in Sweden. The participants were around 70 years of age; they were living together with a spouse, and exhibited an audiogram showing a sensorineural sloping curve (figure 3). The hearing loss was perceived as moderate or substantial and the general health as good (table 7). Their significant other was supportive and did not express negative attitudes towards the patient. The patients were however poor users of coping strategies, both the verbal, non-verbal and maladaptive kind.

For the statistical evaluation, a common battery of standardized methods was used, as was used also in all the studies selected for the present literature review. All studies used almost the same statistical analyses, i.e. the Cronbach's alpha for internal consistency and correlations for the test-retest analysis, the convergent validity assessment and the predictive validity estimation. For the latter, in the current study, also a Student's t-test was conducted between the groups with mild or moderate hearing problems versus the one with substantial or severe hearing difficulties. No factor analysis was performed, because all the DHS items represented the same situation, namely the ability to recognize speech from family members, relatives, and friends. This simplification seemed justified due to the hearing problems experienced group of patients studied here.

DHS seems to possess sufficient psychometric properties with respect to reliability and validity and may be considered to become a reliable and promising a tool in everyday audiological rehabilitation. The reproducibility is high, the internal consistency is good, and DHS correlates highly to all other parts in the general ICF model (fig 1), i.e. activities as represented by the HHIE, environmental factors as assessed by social support and attitudes from others (HHSS), and individual factors (coping with hearing loss; (CPHI). However, DHS correlated poorly to audiometry, both for high and mid frequency PTA, and also to the speech recognition scores in noise, implying a low predictive validity. Studies on previous questionnaires on hearing have presented high, moderate as well as low correlations to the audiometry assessments. For example, in an old study on the HHS (16), the correlation between HHS and pure tone audiometry was high ($r=0.7$), while that to speech discrimination was low ($r=0.2$). Another study on HHS showed moderate correlations both to pure tone audiometry ($r=0.5$) and to speech discrimination tests ($r=0.5$-0.6), (29). For the HHIE, the correlation to pure tone audiometry was moderate ($r=0.6$), (20). To test the predictive validity further, the tot% DHS mean for two groups with regard to self-rated perceived category of hearing problems was compared. The group with patients who perceived their hearing problems as substantial or severe exhibited a significantly higher DHStot% score compared to the group experimenting mild or moderate hearing difficulties (Student's t-test: $p<0.000$), figure 3 and 4 major explanation for the difference between the results from the correlation analysis and the comparisons between the means is that audiometry constitues a poor predictor to hearing problems. In audiology, a well known fact to all professionals is that despite identical audiograms, the perceived hearing problems differ greatly. A main reason for this are differences in daily life, environmental factors and personal factors, just as defined by the ICF model. Another explanation could be that the number of observations in this study is too small because the variation is large. Still, predictive validity needs to be studied further.

Benefits with the present study were the extensive electronic literature search in PubMed, and also the expert panel that guaranteed the content validity. Moreover, most DHS items describe situations well known both from old and validated questionnaires as well as to all audiological professionals and patients. Items are also defined by the ICF with domain and code. Furthermore, DHS is a disease specific clinical psychometric instrument that measures the patient’s level of perceived participation. DHS also directs rehabilitation interventions according to the patient’s explicit desire to change a particular domain according to the ICF. Finally, DHS possesses sufficient psychometric properties with respect to reproducibility, reliability and validity to be an effective and valid instrument.

Shortcomings relate to the large number of questions, which are troublesome to the patient who may get tired, irritated or even confused and thereby impairs the compliance and coherence of from the patient. Also, correlations between DHS and audiometry were poor. It could be argued that the summery variable of a DHStotal% score as used in the current study should be separated into subscales, because hearing function is included in several of the ICF terms (i.e. exchanging information, social relationships, education, work and employment, and civic and community life). Still, the reason for not performing this evaluation on the item level and subscale level was that all DHS items reflect one and same principal body function, i.e. recognizing speech. Therefore, we could see no benefit from having different subscale values. This does not exclude that possibility, if desired due to clinical purposes.

CONCLUSIONS

1. DHS instrument is the first psychometric instrument on hearing that fulfils the requirements from the ICF, changing the basis for the auditory rehabilitation from a medical model focus on impairment, disability and handicap to a biopsychosocial model focused on activity and participation in society.

2. DHS is a disease specific questionnaire based on specific categories from four out of the nine ICF domains.

3. DHS measures the level of perceived participation in common hearing demanding situations, out of which most items are selected from old and already validated questionnaires (HHS, SSHI and HMS).

4. The statistical evaluations showed that the DHS seems to possess sufficient psychometric properties with respect to reliability and validity.

5. DHS has a good potential of becoming a reliable tool and is considered for use both for the prospective patient, their families and the rehabilitation team.

6. One of the most important improvements from the previously used classification is the replacement of the concept of hearing handicap with that of self-rated limitations of participation in auditory demanding situations as experiences from the patient’s own perspective, which introduces new possibilities for assessing auditory rehabilitation outcomes, both short- and long term effects.

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Appendix 1

ICF CODES, first and second level

BODY FUNCTIONS

Chapter 2. Sensory functions and pain

Hearing and vestibular functions (b230-b249)

b230 Hearing functions

b240 Sensations associated with hearing and vestibular function

BODY STRUCTURES

Chapter 2. The eye, ear and related structures

s260 Structure of inner ear

ACTIVITIES AND PARTICIPATION

Chapter 3. Communication *Communicating - receiving (d310-d329)*

d310 Communicating with - receiving - spoken messages

d315 Communicating with - receiving - nonverbal messages

d320 Communicating with - receiving - formal sign language messages

d325 Communicating with - receiving - written messages

d329 Communicating - receiving, other specified and unspecified

Conversation and use of communication devices and techniques (d350-d369)

d350 Conversation

d355 Discussion

d360 Using communication devices and techniques

Chapter 7. Interpersonal interactions and relationships *General interpersonal interactions (d710-d729)*

d710 Basic interpersonal interactions

d720 Complex interpersonal interactions

d729 General interpersonal interactions, other specified and unspecified

Particular interpersonal relationships (d730-d779)

d730 Relating with strangers

d740 Formal relationships

d750 Informal social relationships

d760 Family relationships

d770 Intimate relationships

d779 Particular interpersonal relationships, other specified and unspecified

d798 Interpersonal interactions and relationships, other specified

d799 Interpersonal interactions and relationships, unspecified

DHS 10

Chapter 8. Major life areas

Education (d810-d839)

d810 Informal education

d815 Preschool education d820 School education

d825 Vocational training

d830 Higher education

d839 Education, other specified and unspecified

Work and employment (d840-d859)

d840 Apprenticeship (work preparation)

d845 Acquiring, keeping and terminating a job

d850 Remunerative employment

d855 Non-remunerative employment

d859 Work and employment, other specified and unspecified

Chapter 9. Community, social and civic life

d910 Community life

d920 Recreation and leisure

d930 Religion and spirituality

d940 Human rights

d940 Human rights

d950 Political life and citizenship

ENVIRONMENTAL FACTORS

Chapter 1. Products and technology

e125 Products and technology for communication

Chapter 2. Natural environment and human-made changes to environment

e250 Sound

Chapter 3. Support and relationships

e310 Immediate family

e315 Extended family e320 Friends

e325 Acquaintances, peers colleagues, neighbours and community members

e330 People in positions of authority

e335 People in subordinate positions

e340 Personal care providers and personal assistants

e345 Strangers e355 Health professionals

e360 Health-related professionals

e398 Support and relationships, other specified

e399 Support and relationships, unspecified

Chapter 4. Attitudes (e410-e499)

e410 Individual attitudes of immediate family members

e415 Individual attitudes of extended family members

e420 Individual attitudes of friends

e425 Individual attitudes of acquaintances, peers colleagues, neighbours and community members

e430 Individual attitudes of people in positions of authority

e435 Individual attitudes of people in subordinate positions

e440 Individual attitudes of personal care providers and personal assistants

e445 Individual attitudes of strangers

e450 Individual attitudes of health professionals

e455 Individual attitudes of health-related professionals

e460 Societal attitudes

e465 Social norms, practices and ideologies

e498 Attitudes, other specified

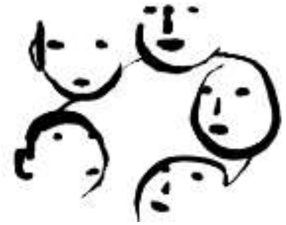
e499 Attitudes, unspecified

Chapter 5. Services, systems and policies (e510-e599)

e535 Communication services, systems and policies

PERSONAL FACTORS

Are not yet developed.

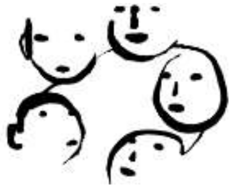


Appendix 2 DHS

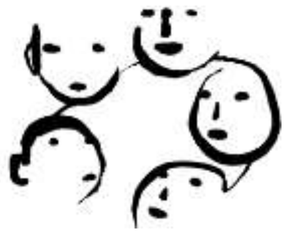
Skattning av upplevd delaktighet i hörselkrävande situationer

Med FULL DELAKTIGHET menas att man i den utsträckning och på det sätt man önskar…	MIN DELAKTIGHET ÄR (markera med en ring runt lämplig siffra)						SÄTT EN RING RUNT LÄMPLIGT SVAR	
	Obetydligt begränsad	Lätt begränsad	Måttligt begränsad	Mycket begränsad	Starkt/totalt begränsad	Inte aktuellt	Jag är nöjd med min delaktighet	Jag vill ha hjälp att öka min delaktighet
1. kan deltaga i en konversation med en person när det är tyst i bakgrunden	0	1	2	3	4	5	Ja Nej	Ja Nej
2. kan deltaga i en konversation i en grupp med flera personer i en för övrigt tyst miljö?	0	1	2	3	4	5	Ja Nej	Ja Nej
3. kan höra när det någon viskar i Ditt öra	0	1	2	3	4	5	Ja Nej	Ja Nej
4. kan deltaga i konversation under en middagsmåltid med flera personer	0	1	2	3	4	5	Ja Nej	Ja Nej

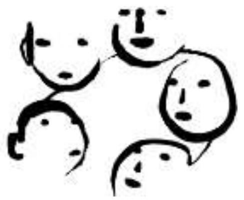
Med FULL DELAKTIGHET menas att man i den utsträckning och på det sätt man önskar…	MIN DELAKTIGHET ÄR (markera med en ring runt lämplig siffra)						SÄTT EN RING RUNT LÄMPLIGT SVAR	
	Obetydligt begränsad	Lätt begränsad	Måttligt begränsad	Mycket begränsad	Starkt/totalt begränsad	Inte aktuellt	Jag är nöjd med min delaktighet	Jag vill ha hjälp att öka min delaktighet
5. kan deltaga i en konversation under en fest	0	1	2	3	4	5	Ja Nej	Ja Nej
6. kan deltaga i en konversation under resa med t.ex. bil, buss eller tåg	0	1	2	3	4	5	Ja Nej	Ja Nej
7. kan deltaga i en konversation under restaurangbesök	0	1	2	3	4	5	Ja Nej	Ja Nej
8. kan deltaga i föreningslivet	0	1	2	3	4	5	Ja Nej	Ja Nej
9. kan prata i telefon eller mobil med en person Du inte känner när det är tyst i bakgrunden	0	1	2	3	4	5	Ja Nej	Ja Nej



Med FULL DELAKTIGHET menas att man i den utsträckning och på det sätt man önskar…	MIN DELAKTIGHET ÄR (markera med en ring runt lämplig siffra)						SÄTT EN RING RUNT LÄMPLIGT SVAR	
	Obetydligt begränsad	Lätt begränsad	Måttligt begränsad	Mycket begränsad	Starkt/totalt begränsad	Inte aktuellt	Jag är nöjd med min delaktighet	Jag vill ha hjälp att öka min delaktighet
10. kan lyssna på TV när ljudet är inställt så att volymen är anpassad för andra och inte för dig själv	0	1	2	3	4	5	Ja Nej	Ja Nej
11. kan uppleva kulturella aktiviteter såsom teater, opera eller bio	0	1	2	3	4	5	Ja Nej	Ja Nej
12. kan känna igen personer på rösten utan att se deras ansikten	0	1	2	3	4	5	Ja Nej	Ja Nej
13. kan vakna av väckarklockans signal	0	1	2	3	4	5	Ja Nej	Ja Nej
14. kan höra vilket håll en buss eller bil kommer ifrån när Du står på en trafikerad gata	0	1	2	3	4	5	Ja Nej	Ja Nej



Med FULL DELAKTIGHET menas att man i den utsträckning och på det sätt man önskar…	MIN DELAKTIGHET ÄR (markera med en ring runt lämplig siffra)						SÄTT EN RING RUNT LÄMPLIGT SVAR	
	Obetydligt begränsad	Lätt begränsad	Måttligt begränsad	Mycket begränsad	Starkt/totalt begränsad	Inte aktuellt	Jag är nöjd med min delaktighet	Jag vill ha hjälp att öka min delaktighet
15. kan ha kontakt med familj eller nära släktingar	0	1	2	3	4	5	Ja Nej	Ja Nej
16. kan ha kontakt med vänner och bekanta	0	1	2	3	4	5	Ja Nej	Ja Nej
17. kan deltaga i religiösa eller andliga aktiviteter	0	1	2	3	4	5	Ja Nej	Ja Nej
18. kan utöva sina fritidsysselsättningar	0	1	2	3	4	5	Ja Nej	Ja Nej
19. kan yrkesarbeta	0	1	2	3	4	5	Ja Nej	Ja Nej



Med FULL DELAKTIGHET menas att man i den utsträckning och på det sätt man önskar…	MIN DELAKTIGHET ÄR (markera med en ring runt lämplig siffra)						SÄTT EN RING RUNT LÄMPLIGT SVAR	
	Obetydligt begränsad	Lätt begränsad	Måttligt begränsad	Mycket begränsad	Starkt/totalt begränsad	Inte aktuellt	Jag är nöjd med min delaktighet	Jag vill ha hjälp att öka min delaktighet
20. kan deltaga i möten och diskussioner på jobbet	0	1	2	3	4	5	Ja Nej	Ja Nej
21. kan ha kontakt med någon utomstående t ex en kollega, hemtjänst, eller liknande	0	1	2	3	4	5	Ja Nej	Ja Nej
22. kan ha möjlighet till utbildning på alla nivåer även fortutbildning, vidareutbildning och yrkesträning	0	1	2	3	4	5	Ja Nej	Ja Nej
23. kan ha en nära relation till din samlevnads partner	0	1	2	3	4	5	Ja Nej	Ja Nej
24. kan bistå eller hjälpa andra	0	1	2	3	4	5	Ja Nej	Ja Nej

Summering och prioritering

Du har nu tänkt till och markerat hur du upplever din grad av delaktighet, om du är till freds med din delaktighet eller inte, samt om du vill förändra din situation eller inte.

Här vill vi att du väljer ut de 3 situationer, som det känns viktigast för dig att förändra.

Jag vill helst öka min delaktighet i situation nr ………………..
Därefter vill jag öka min delaktighet i situation nr……………..
Jag vill även öka min delaktighet i situation nr………………..

Om Du vill berätta något ytterligare om Din situation, kan Du göra det här.

Övriga Frågor

1. Vilket år är Du född?..

2. Civilstånd:
   Gift………Sambo……..Ensamstående………..

3. Vilken utbildning har du?

   Folkskola / grundskola / realskola/ yrkesskola / gymnasium / universitet / högskola / annat ………

   Antal utbildningsår sammanlagt: ………………… år

4. Yrke: ……………………………………………

5. Närmast anhörig: Make/maka Barn Annan:……

6. Hur många bekanta umgås du med? ………………

7. Har du barn? Ja Antal: …….barn Nej

8. Har du barnbarn? Ja Antal: …......barnbarn Nej

9. Är du med i en förening? Ja, passiv medlem Ja, aktiv medlem Nej

10. Hur länge har Du hört dåligt? …………………… år

11. Har du tinnitus (ljud/ pip i öronen)?
    Aldrig……sällan…….. ibland…….. .ofta……alltid…..

12. Hur skulle Du själv skatta graden av Dina hörselproblem?

    Lindrig…… måttliga …….ordentliga…. svåra……..

13. Är Du frisk för övrigt? Ja Nej

14. Äter Du mediciner? Ja Nej

    Om ja, vad? Du behöver inte ange dos, bara medicinens namn. Använd baksidan.

Anvisningar

Du graderar här om du utifrån ditt eget perspektiv upplever din delaktighet begränsad i olika situationer och i så fall hur mycket (0 = *obetydligt; 1 = lätt; 2 = måttligt;3 = mycket; 4 = starkt/totalt begränsad).* Informationen hjälper oss att tillsammans med dig formulera meningsfulla mål för din rehabilitering.

Frågeformuläret har tre delar:

1. 14 påståenden om *delaktighet i olika situationer*.
2. Efter varje påstående, följer frågor om du är *nöjd* med graden av din delaktighet. Vidare om du önskar hjälp att öka din grad av delaktighet.
3. Formuläret avslutas med att Du väljer ut de *tre situationer där du helst* vill öka din delaktighet.

För varje påstående (14 st), ber vi dig gradera hur du upplever din delaktighet i olika situationer genom att markera med en *cirkel runt den siffra* som känns rätt för dig. ”Full delaktighet” betyder att kunna ta del av och ”vara involverad i” situationer och aktiviteter på det sätt, och i den omfattning man önskar.

Exempel 1. Om du upplever att du har full kontroll över en konversation, så är din delaktighet inte begränsad (alternativ 0).

Exempel 2. Om du inte är involverad i en konversation i den omfattning och på det sätt du önskar, så är din delaktighet begränsad med en grad från ”lätt” till ”totalt”.

Exempel 3. Om du inte är intresserad av eller det inte är aktuellt för dig att delta i en konversation, markera då 0 i kolumnen ”inte aktuellt”. Detta gäller t.ex. om Du inte tittar på TV eller inte går på teater eller bio.

OBSERVERA att när du graderar din delaktighet ska svaret markera det som du upplever passar bäst in på din livssituation. Det är din egen åsikt och erfarenhet som är viktig.

På frågorna om du är nöjd med, eller önskar öka din grad av delaktighet, ska du markera *ja eller nej*.

I slutet ber vi Dig ange de tre situationer där du främst vill öka din delaktighet i.

Lycka till!

Appendix 3

Frågeformulär om hörsel (HHSS)

I detta häfte finns 21 påståenden och Du ska tänka efter hur dessa påståenden **gäller för Dig – just nu**. Under varje påstående finns fem svarsalternativ och vi ber Dig ringa in det som bäst stämmer för **Din egen del – just nu**.

1. Mina närstående accepterar att jag hör dåligt.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

2. Mina närstående är bekymrade över att jag hör dåligt.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

3. Mina vänner är bekymrade över att jag hör dåligt.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

4. Mina närstående beklagar sig över min nedsatta hörsel.

Stämmer absolut inte stämmer inte stämmer i någon mån stämmer stämmer helt och hållet

5. Mina närstående uppmuntrar mig att söka hjälp för mina hörselproblem.

Stämmer absolut inte stämmer inte stämmer i någon mån stämmer stämmer helt och hållet

6. Min nedsatta hörsel gör att människor blir irriterade på mig.

Stämmer absolut inte stämmer inte stämmer i någon mån stämmer stämmer helt och hållet

7. När jag vill tala om mina hörselproblem så försöker mina anhöriga förstå.

Stämmer absolut inte stämmer inte stämmer i någon mån stämmer stämmer helt och hållet

8. Genom att jag hör dåligt blir jag mer beroende av andra än vad jag skulle vilja vara.

Stämmer absolut inte stämmer inte stämmer i någon mån stämmer stämmer helt och hållet

9. Människor omkring mig vet att jag hör dåligt och försöker hjälpa mig.

Stämmer absolut inte stämmer inte stämmer i någon mån stämmer stämmer helt och hållet

10. Människor behandlar mig annorlunda pga min dåliga hörsel.

Stämmer absolut inte stämmer inte stämmer i någon mån stämmer stämmer helt och hållet

11. Jag är säker på att någon av mina närstående skulle hjälpa mig om jag bad dem om hjälp pga min nedsatta hörsel.

Stämmer absolut inte stämmer inte stämmer i någon mån stämmer stämmer helt och hållet

12. Min dåliga hörsel gör min närstående upprörda.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

13. Mina närstående och vänner ursäktar mig inför andra pga min dåliga hörsel.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

14. I kontakten med mina närstående är min hörselnedsättning källa för konflikter.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

15. Jag tror att min hörselnedsättning gör människor omkring mig nervösa.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

16. Mina närstående och vänner anser att min hörselnedsättning är ett större problem än vad jag själv anser.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

17. Mina närstående visa att de bryr sig min dåliga hörsel.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

18. Det finns åtminstone en bland mina anhöriga som är förstående.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

19. Mina närstående känner sig bevärade av min nedsatta hörsel.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

20. Mina närstående lyssnar när jag beklagar mig angående mina hörselproblem.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

21. Mina närstående blir förargade på mig pga min hörselnedsättning.

Stämmer absolut inte stämmer inte stämmer i någon mån
stämmer stämmer helt och hållet

Appendix 4

FRÖLUNDA
SPECIALISTSJUKHUS

Frågeformulär för Hörselindex 65+ - Screening med 10 frågor

Namn:____________________________________ Födelsenr:___________

1. Får problem med hörseln dig att känna dig generad när du träffar nya människor?

☐ Ja

☐ Ibland

☐ Nej

2. Får problem med hörseln dig att känna dig frustrerad när du pratar med dina familjemedlemmar?

☐ Ja

☐ Ibland

☐ Nej

3. Har du svårt att höra när någon viskar?

☐ Ja

☐ Ibland

☐ Nej

4. Känner du dig nedsatt i din funktion i allmänhet på grund av problem med hörseln?

☐ Ja

☐ Ibland

☐ Nej

5. Gör problem med hörseln att det är svårt för dig att hälsa på vänner, släktingar eller grannar?

☐ Ja

☐ Ibland

☐ Nej

Var god vänd

6. Gör problem med hörseln att du deltar mindre än du vill i olika intressen/aktiviteter/teater-biobesök/kyrkbesök etc?

☐ Ja

☐ Ibland

☐ Nej

7. Är problem med hörseln en orsak till gräl med familjemedlemmar?

☐ Ja

☐ Ibland

☐ Nej

8. Är det svårt att höra på TV eller radio på grund av hörselproblem?

☐ Ja

☐ Ibland

☐ Nej

9. Upplever du någon form av nedsättning av din hörsel som gör att du blir begränsad eller hindrad i ditt personliga eller social liv?

☐ Ja

☐ Ibland

☐ Nej

10. Besväras du av problem med hörseln vid restaurangbesök tillsammans med släktingar eller vänner?

☐ Ja

☐ Ibland

☐ Nej

*Översättning med tillstånd från Ventry I, Weinstein B (1982) The hearing Handicap Inventory for Elderly: A new tool. Ear Hear; 3: 128-134

Appendix 5

Frågeformulär om kommunikationsstrategier (CSS/CPHI)

Nedanstående 25 påståenden beskriver **olika sätt att bete sig vid samtal** med andra människor. Tänk efter **hur det brukar vara för Dig** och markera det svarsalternativ som bäst stämmer in på hur Du reagerar eller hur ofta en situation inträffar.

1. Ett sätt som jag använder för att få folk att upprepa vad de sagt är att låtsas att jag inte hört något alls.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
2. Om folk upprepar vad de sagt och jag fortfarande inte förstår, ber jag dem säga det ytterligare en gång.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
3. Under svåra lyssningsförhållanden försöker jag placera mig så att jag kan höra så bra som möjligt.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid

4. Jag avbryter andra när det är svårt att höra vad de säger.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
5. Om jag hör delar av vad någon säger, ber jag dem bara upprepa det jag inte hörde.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
6. När jag har svårt att uppfatta vad någon säger, tittar jag noga på hans eller hennes ansikte.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
7. Jag brukar vara den som dominerar i samtal, så jag inte behöver lyssna till andra.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
8. Jag har bett mina närmaste att fånga min uppmärksamhet innan de tilltalar mig.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid

9. Om jag sitter så att jag inte kan höra, flyttar jag mig till en bättre plats.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
10. Om någon verkar irriterad över att behöva upprepa, slutar jag att fråga och låtsas att jag förstår.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
11. När jag inte uppfattar vad folk säger, så ber jag dem upprepa det.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
12. På fester eller andra tillställningar försöker jag hålla mig till väl upplysta platser så att jag kan se människors ansikten.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
13. Jag brukar undvika situationer där jag tror att jag kommer att få svårt att höra.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid

14. När jag har svårt att förstå vad familj eller vänner säger, påminner jag dem om att jag har nedsatt hörsel.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
15. När jag måste lyssna i en grupp, försöker jag sitta där jag kan höra bäst	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
16. Jag undviker att samtala med andra på grund av min dåliga hörsel.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
17. Jag har bett vänner och arbetskamrater att fånga min uppmärksamhet innan de tilltalar mig.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid

18. När det finns ljud i bakgrunden, placerar jag mig så att det stör mig så litet som möjligt.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
19. När jag inte förstår vad någon har sagt, låtsas jag att jag har förstått.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
20. När jag inte uppfattar vad folk säger, förklarar jag att jag har nedsatt hörsel.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
21. När jag har svårt att följa med i ett samtal, lyssnar jag noga och försöker uppfatta det viktigaste.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
22. Jag undviker att tala med okända människor på grund av min dåliga hörsel.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid

23. När jag tycker att någon talar för tyst, ber jag honom eller henne att tala högre.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
24. Om det är möjligt försöker jag se ansiktet på den som talar.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid
25. När jag inte hör vad folk säger, så låtsas jag inte om dem.	☐ Nästan aldrig	☐ Ibland	☐ Ungefär varannan gång	☐ Ganska ofta	☐ Nästan alltid

Appendix 6

GÖTEBORGS UNIVERSITET
Sahlgrenska akademin
Institutionen för neurovetenskap och fysiologi

Enheten för Audiologi

Information om ett forskningsprojekt om hörsel

Studiens bakgrund och syfte:

Problem på grund av hörselnedsättning kan mätas bland annat med hjälp av frågeformulär.
De som finns idag behöver förbättras. Vi har därför utvecklat ett nytt frågeformulär, kallat ”Självskattning av upplevt deltagande i hörselkrävande situationer” (förkortat SUD-hörsel). Syftet med detta projekt är att undersöka SUDs kvalitet och tillförlitlighet.

Förfrågan om deltagande:

Eftersom Du har genomgått en hörsel mätning frågar vi om Du vill delta i projektet. Din insats innebär att Du vid två olika tillfällen besvarar ett frågeformulär, vilka handlar om hur Du hör och agerar i olika lyssnarsituationer. Tidsåtgången beräknas vara max 30 minuter per gång. I studien används också mätvärdena från Ditt hörseltest. Deltagandet i denna studie är helt frivilligt. Du kan när som helst, utan närmare förklaring och utan att detta påverkar övrig behandling, avbryta Ditt deltagande i studien. Samtycke lämnas skriftligt på separat papper.

Fördelar, risker, försäkringsfrågor:

Projektet innebär varken fördelar eller risker för Dig som deltar. Vi kommer därför inte ha skade-försäkring eller andra försäkringar du får heller ingen ersättning för förlorad inkomst.

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Hantering av data och sekretess:

För att kunna bearbeta dessa uppgifter krävs att dessa lagras och bearbetas i ett dataregister. Dina personuppgifter ersätts då av ett löpnummer så att enskild individ inte urskiljs. Dina svar och resultat kommer att vara sekretesskyddade och behandlas så att inte obehöriga kan ta del av dem. Resultaten kommer att lagras i enlighet med personuppgifts lag. Studiens resultat kommer att presenteras i form av en uppsats. Ansvarig för behandlingen av dina personuppgifter är Utförarstyrelsen för Habilitering och Hälsa. Du kan vända dig till förvaltningens personuppgiftsombud, Rolf Johansson, Regionens Hus, 462 80 Vänersborg, tel. 0521-275240 om du önskar utdrag över de personuppgifter som finns registrerade på dig eller hjälp med ev. rättelse.

Ansvariga för genomförandet av studien är

Ansvarig handledare
Marie-Louise Barrenäs, docent och överläkare
Växthuset
Drottning Silvias Barn och Ungdomssjukhus
Tel 031-343 8224
e-mail: marie-louise.barrenas@vgregion.se

Forskare
Soraya Khosravi, Audionom

Habilitering och Häls
Hörsel och dövverksamheten,
Hörsel, diagnostik och rehabilitering

Västra Götaland regionen
421 22 Göteborg Tel: 0704 789293

Ansvarig forskare
Ann-Kristin Espmark, dr leg audionom

institutionen för neurovetenskap och fysiologi
Arvid Wallgrens Backe, hus 3
Box 452, 405 30 Göteborg

Tel: 031-786 5784

Appendix 7

GÖTEBORGS UNIVERSITET
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Enheten för Audiologi

Samtyckesformulär

Jag har muntligen informerats och tagit del av ovanstående skriftliga information om forskningsstudien och den databehandling av personuppgifter som studien innebär. Jag har också kunnat ställa frågor och fått dem besvarade.

Jag är medveten om att mitt deltagande i studien är fullt frivilligt och att jag när som helst och utan närmare förklaring kan avbryta mitt deltagande utan att detta påverkar mitt fortsatta omhändertagande.

Jag samtycker härmed till att delta i denna studie, samt till databehandling av mina personuppgifter och testresultat.

____
Ort och datum

____
Patientens namnteckning

____

Namnförtydligande

Ansvariga för genomförandet av studien är

Handledare namnteckning
Marie-Louise Barrenäs, docent och överläkare
Växthuset
Drottning Silvias Barn och Ungdomssjukhus
Tel 031-343 8224
e-mail: marie-louise.barrenas@vgregion.se

Forskare namnteckning
Soraya Khosravi, Audionom

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