

The ICF Core Sets for Hearing Loss Project: Functioning and Disability from the Patient Perspective

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Abbreviations:

ICF	International Classification of Functioning, Disability and Health
HL	Hearing Loss
WHO	World Health Organization

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Abstract

Objective: To explore areas of functioning, disability and environmental factors of adults with hearing loss (HL) by using the ICF classification as a tool to determine and document each element. *Design:* A qualitative study applying mainly focus-group methodology was applied). *Study sample:* Dutch and South African adults (≥ 18 years of age) with HL (20-95 dB HL) who used oral communication as first communication. Summative content analysis was performed on the transcripts by linkage to appropriate ICF categories. *Results:* 143 ICF categories were identified, most of which belonged to the Activities & Participation (d) component, closely followed by the Environmental factors component. Informants specifically mentioned categories related to oral communication and interaction. Assistive technology (such as hearing aids), noise, and support by and attitudes of others in the environment of the informants were considered highly influential functioning and disability. *Conclusions:* The present study illustrates the complexity and comprehensiveness of aspects involved in functioning and disability of adults with HL. The findings highlight the necessity of using a multidimensional tool, such as the ICF, where both internal and external aspects are valued and considered in the analysis.

Introduction

Hearing loss is usually described by psycho-acoustic measurements such as pure tone audiometry and speech audiometry. While these tests are appropriate for measuring specific functions, they appear to be limited in predicting the consequences that a hearing loss has on a person's daily activities and involvement in life situations. This is illustrated by the generally fair-to-moderate correlations between psycho-acoustic measurements and disability-based questionnaires that are reported (e.g., Chang et al., 2009). A limitation to disability-based

questionnaires related to hearing loss is the large number of instruments available and the clear lack of consensus of which questionnaire to use (Granberg et al. 2014a). Reviews have revealed that during the last decades, over 60 different questionnaires have been used to assess the effects of hearing loss (Bentler & Kramer, 2000; Kramer, 2005; Noble, 1998), with new ones still being developed.

The perspective currently often employed when mapping functioning with hearing loss is a 'consequences' - perspective: What are the hearing functions, daily activities, and life situations negatively affected by the hearing loss and to what extent? However, there are many contextual factors within or outside the individual that can influence a person's functioning with hearing loss, both negatively and positively. In disability models, contextual factors may act as moderating or mediating variables in, for instance, the relationship between health related activities and the engagement in life situations (Wang et al., 2006). For example, a hearing aid (contextual factor) may be purchased because of problems in one-to-one conversing (a health related activity) and cause less communication problems when socializing (engaging in life situations). In this case, the hearing aid is a moderating factor, as it influences the extent to which the health related activity influences the engagement in life situations. Conversation problems may also increase perceived hearing loss stigma, in turn strengthening withdrawal from vital activities such as socializing. In this case, hearing loss stigma is a mediating factor and is part of the causal pathway between problems with a health related activity and the engagement in a life situation. Numerous studies have identified such environmental factors, such as hearing aids (Mulrow et al., 1990), the acoustical environment (Gatehouse & Noble, 2004), hearing loss stigma (Hétu, 1996), and applied coping strategies (Garstecki & Erler, 1999). Consequently, failing to map such factors would yield an incomplete understanding of a person's functioning and personal situation.

The importance of applying a multidimensional approach in treating patients with hearing loss is increasingly acknowledged within the clinical audiological setting (e.g., Boothroyd, 2007). However, there is still no consensus of which measurement instruments to be used, or, more fundamentally, what particular aspects of human functioning and disability should be obtained to perceive a multidimensional view of an adult's functioning with hearing loss.

The International Classification of Functioning, Disability and Health (ICF) is a framework providing a common language for describing health and health-related states. It merges a biomedical paradigm with a social paradigm such that a wider understanding of human functioning can be facilitated. It applies a 'components of health' classification. In other words, the *constituents* of human functioning rather than just the consequences of a disease or condition, can be described. A person's functioning is described in terms of the person's body (*Body functions and Body structures component*) and in terms of the activities the person executes and the situations the person is involved in (*Activities & Participation component*) (WHO, 2001). *Body functions* are the physiological functioning of body systems, whereas *body structures* are anatomical parts of the body. *Activities* refer to the execution of a task or action by an individual and *Participation* refers to involvement in life situations. In the ICF, *Functioning* is the umbrella term for all body functions, activities, and participation, and *Disability* is the umbrella term for all impairments, activity limitations, and participation restrictions. The ICF also states that a person's functioning can be influenced by *contextual factors* (*Environmental* and *Personal factors*). Environmental factors make up the physical, social, and attitudinal environment in which people live and conduct their lives, while Personal factors relate to the intrinsic part of the individual not related to the health condition such as the person's age or sex. All possible Body functions and structures, Activities &

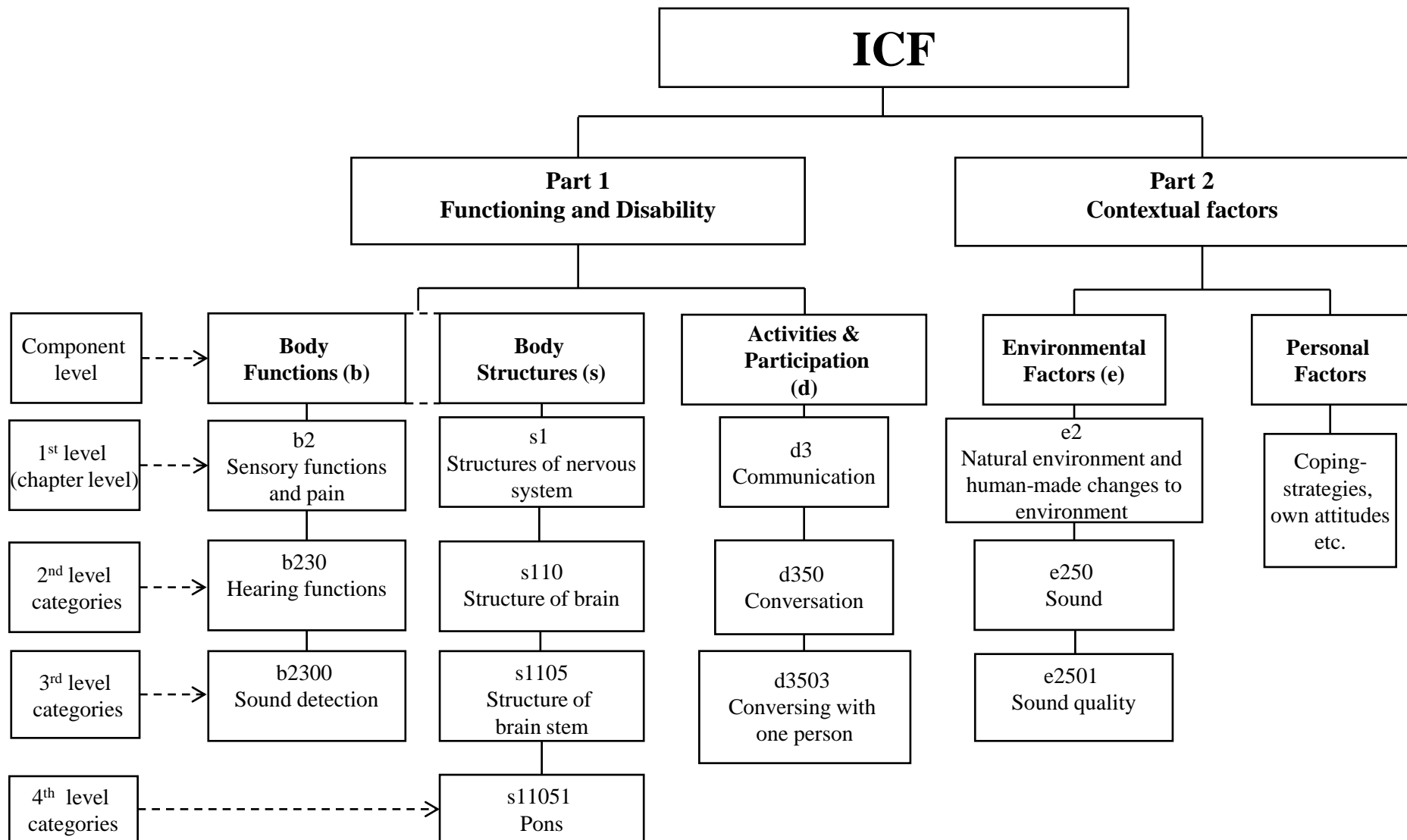


Fig 1. The hierarchical structure of ICF with examples from each level is provided. Note that all levels are connected to each other; the deeper category contains a more detailed specification of the previous category. The personal factors component lacks categories. Figure adopted from Granberg et al. in press.

Participation and Environmental factors are listed as health domains in the classification. ICF is hierarchical, with numerical category codes for use when assessing health related information (Fig.1).

The ICF has become a universally accepted framework across various medical disciplines (ICF Research Branch., 2012). Although some efforts have been made toward the adoption of the ICF in scientific and clinical audiological work (Hickson & Scarinci, 2007), general knowledge of the ICF and its use in daily practice are not yet widespread within the audiological community. One reason for this may be that the ICF contains a large number of categories (1424) on different levels. This issue has been identified in other disciplines as well, and, hence, the WHO initiated the development of *ICF Core Sets*. A Core Set is a set of ICF categories of particular relevance for a specific health condition, target group or situation. So far, 31 Core Sets have been developed for various health conditions, target groups or situations (ICF Research Branch, 2012).

In 2008, the international project ICF Core Sets for Hearing Loss was initiated (Danermark et al., 2010). Its final aim was to develop two Core Sets (a Comprehensive and a Brief) that comprehensively describe the functioning and disability of adults with hearing loss. The WHO has developed a rigorous procedure to obtain the Core Sets consisting of three phases: a preparatory phase (I), a consensus phase (II), and a validation phase (III). The first phase comprises four scientific studies involving the researcher perspective (a systematic review), the patient perspective (a focus group study and a multicentre study), and the expert perspective (a web survey) (Danermark et al., 2010). To date, phase I and II of the project have been carried out (Danermark et al., 2013; Granberg et al., 2014ab).

The current paper reports on the findings of one of the preparatory studies in phase I, namely the focus group study. When applying the ICF perspective to assess functioning and disability, potentially important influencing contextual factors would be the influence of personal factors. This component currently lack categories due to large social and cultural variations associated with the content of that component (WHO, 2001, pp. 8). Nonetheless, a thorough documentation of the personal factors important for functioning and disability revealed by the informants was made in this study. The results from that documentation will be presented and discussed in a separate paper.

The objective of the present study was:

- To explore areas of functioning, disability and environmental factors of adults with hearing loss by using the ICF classification as a tool to determine and document each element

This study will provide an in-depth insight into what adults with hearing loss themselves report as important factors in the functioning with hearing loss as one significant aspect in the development of ICF Core Sets for Hearing loss.

Methods

Design

A qualitative study was adopted. Focus groups were used as the main data collection method. Three groups were held in South Africa (SA) and three in the Netherlands (NL). The countries were chosen based on their differences in development status. SA is classified as a developing country, while NL is concerned a developed country. The choice of six focus groups in this study was based on previous reports on ICF core set projects, where 4 to 6

focus groups were required to collect sufficient information about functioning and contextual factors to reach data saturation (e.g. Boonen et al., 2009; Coenen et al., 2011; Gradinger et al., 2011). The focus groups were organized according to three age groups (18-40 years, 41-60 years and 61 years and above). It was assumed that persons of similar ages and life phases (i.e., with regard to work and family life) would stimulate group interaction and discussion, yielding richer data. Focus group size is normally based on aspects such as topic complexity, with 6 to 10 participants being optimal (Morgan, 1998). However, in the present study the hearing disability was taken into consideration and therefore it was decided that smaller groups should be used to facilitate communication between group members.

Additional interviews

In SA, two of the focus groups (41-60 and ≥ 61) included limited participants as a result of recruitment difficulties and last minute dropouts. It was therefore decided to supplement the focus group data from SA with individual face-to-face interviews following the same ICF protocol as for the focus groups. Eight additional interviews were conducted (four in each age group).

Participantss

Inclusion criteria

Individuals were included if they: 1) fulfilled the clinical criteria for degree of hearing loss, i.e., *mild* (20- <40 dB HL), *moderate* (40-<70 dB HL), *severe* (70- <95 dB HL) or *profound hearing loss* (≥ 95 dB HL) (HEAR, 1996); 2) were at least 18 years old; 3) used oral language as first communication mode; 4) were conversant in *English* (SA) or *Dutch* (NL); 5) were willing to share and discuss aspects of functioning, disability and contextual factors in relation to self- experienced hearing loss; 6) had understood the purpose of the study, and 7) had signed an informed consent.

Sampling

Purposeful sampling was applied with a maximum variation strategy (Quinn Patton, 2002). In purposeful sampling, the participants are chosen for their ability to provide the researcher with information. A maximum variation strategy means that a number of characteristics important for the studied phenomena are identified and maximum diversity of these characteristics is strived for in the sample (Ayres, 2007). In this study, maximum variability was applied according to age, sex and degree of hearing loss. In SA there was also an effort made to obtain maximum variation in the following demographic characteristics: cultural backgrounds (home language), ethnicity, and levels of education.

Recruitment

In SA participants were recruited from patient population of the Department of Speech-Language Pathology and Audiology, University of Pretoria In the Netherlands, participants were recruited from the patient population of the Audiological Center of the VU University Medical Center in Amsterdam. The present study was approved by the Medical Ethics Committee of the VU University Medical Center in Amsterdam, the Netherlands, and by the Research Ethics Committee of the Faculty of Humanities, University of Pretoria, South Africa.

Altogether, 36 informants participated in the study (Table 1).

Context

The two countries differed significantly from several perspectives. SA is a multicultural country with eleven official languages and a heterogeneous population in segments of developed and developing settings and with an estimated population of 50.59 million (Statistics South Africa, 2011). NL is classified as one of the wealthiest countries in the world (Eurostat, 2013), with one official language and a population of around 17 million inhabitants. About 21% of the population is classified as immigrants (persons with at least one parent born

Table 1. Characteristics of the informants.

		South African sample (n=20)	Dutch sample (n=16)
Sex (%)	Males	65	44
	Females	35	56
Age in age groups (M & Range)	18-40	29.6 (25-39)	29.8 (29-31)
	41-60	53.4 (42-62*)	49.0 (42-53)
	≥61	76.3 (72-84)	72.3 (62-87)
Type of HL (%)	Conductive	-	12.5
	Sensorineural	60	75
	Mixed	40	12.5
Degree of HL (%)	Mild	20	25
	Moderate	55	50
	Severe	20	6
	Profound	5	19
Highest educational level (%)	University	25	
	High School	40	
	Secondary school	15	
	Primary School	15	
	(Missing data)	(5)	
Self- reported first language (%)	Afrikaans	45	
	Zulu	25	
	English	10	
	Sotho	5	
	Sepedi	5	
	Ndebele	5	
	(Missing data)	(5)	

*One of the informants true age turned out to be 62 instead of 60 years old, but It was nonetheless decided to let the person stay and participate in the focus group session. As the person was still active in the work force. It would not have a negative influence on the group discussion in any substantial way.

abroad); however, the majority of the immigrants (55%) are of Western origin (Verweij et al., 2012).

Procedures

The focus groups in SA were all chaired by one moderator and one assistant who was responsible for taking notes, observing the group and audio recording of the discussions. The individual interviews were carried out by two interviewers together. The moderator/interviewers were clinical research audiologists, with experience in moderating/interviewing groups and individuals with hearing loss. In NL, the moderator was a psychologist working in the field of audiology, trained in focus group moderation and had chaired several focus groups in the past.

Each focus group session/interview was recorded and later transcribed verbatim. The informants filled out a form containing brief questions about socio-demographic information and some details regarding their hearing loss. After a short introduction, seven open-ended questions were formulated based upon the different ICF components *Body functions*, *Body structures*, *Activities & Participations*, *Environmental factors* and *Personal factors*. If necessary, the moderator added probing questions or clarified the questions. The questions were based on questions used in former Core-Sets projects modified to fit the target group of adults with HL. The following questions were used:

1. How does your hearing loss affect you? (Probe: How does it affect your health, your feelings?)
2. If you think about your body, in which parts are your problems?
3. If you think about your daily life, how does your hearing loss affect the things you can and cannot do?
4. If you think about your environment and where you work and live, what and/or whom do find helpful and supportive?

5. If you think about your environment and where you work and live, what and/or who makes it difficult for you?
6. If you think about yourself and about your hearing loss – what helps you to handle your hearing loss?
7. If you think about yourself and about your hearing loss – what makes it difficult for you to handle your hearing loss?

Qualitative data analysis

The method of data analysis applied in the current study was based on summative content analyses described by, e.g., Hsieh and Shannon (2005). All data were connected (i.e. *linked*) to the ICF framework, using a specific analysis method called '*the seven steps linking procedure*' was developed. This method combines the established ICF linking rules designed for connecting different kinds of scientific data to ICF (Cieza et al., 2002; Cieza et al., 2005) and the linking rules developed especially for audiological data (Granberg et al., 2014b). The method used in the present analysis consisted of seven steps: 1) *identification of a meaning unit*, 2) *definition of the meaningful concept(s)*, 3) *interpretation of the underlying meaning*, 4) *determination of the linking uni(s)*, 5) *deriving the appropriate ICF category*, 6) *documentation of linking rule applied* and 7) *checking the representativeness of the chosen ICF categories*. The method is fully explained in Appendix 1, with an example provided in Table 2. As is customary within content analysis, a transcribed interview is viewed as a *unit of analysis*. In this study, each focus group represented a unit of analysis. As stated above, in SA additional individual interviews were also conducted. These were added to the units of analysis of the different focus groups from South Africa. Altogether, this resulted into six units of analysis used for further analysis. The frequencies of ICF categories were calculated across units of analysis. In order to avoid favoring groups/informants that, e.g., expressed statements repeatedly, an ICF category was only counted once within a unit of analysis, even

Table 2. Example of content analysis of the verbatim transcription according to the seven- steps linking procedure.

1. Meaning unit	2. Meaningful concept	3. Interpretation of the underlying meaning	4. Linking unit	5. ICF category	6. Linking rule
<p>“I feel embarrassed because I feel...eh, you know, my students and my colleagues expect, you are a professor, you should know what’s happening, you know”</p>	<p><u>I feel embarrassed</u> <u>students and colleagues expect you to know things since you are a professor</u></p>	<p>Others expect me to behave and interact as an professor and when I fail in doing that, it makes me embarrassed</p>	<p>I feel embarrassed</p>	<p>b152 embarrassed</p>	<p>Cieza, rule 3</p>
			<p>Attitudes of colleagues and students</p>	<p>e425</p>	
			<p>Interaction according to social rules</p>	<p>d7203</p>	

The seventh step (not shown in the table) consists of checking the representativeness of chosen ICF categories.

if it had appeared several times within the unit of analysis. The maximum appearance of a single ICF category was therefore six (one per unit of analysis). The analyses of the data were conducted by two of the authors (SB and MP) separately who were well trained in ICF and in the linking procedure. The authors checked and reanalyzed a proportion of the analyses of their colleagues' (translated) data in order to assure quality assurance.

Not covered

In all units of analysis, some of the revealed information could not be assigned to any ICF category. In accordance with the established linking rules, this type of information was coded as *nc* (not covered by ICF) (Cieza et al., 2005). Some information was recognized as 'nc' but could still be assigned to a specific ICF component. This information was coded with the component letter in combination with *nc*, e.g. *e-nc*, as suggested and performed in a former preparatory study in the project (Granberg et al., unpublished data). The identified concepts coded as 'component not covered' were further analyzed and sub-categorized but not included in this study.

Results

ICF categories

In total, 2508 meaning units were identified in the transcripts and further analyzed. This resulted in the identification of 143 units which could each be classified in unique ICF categories (Table 3). Of these, 55 % were linked to third level categories, 38 % to second level categories, 6 % to first level (chapter level), and <1% to fourth level categories.

Nineteen ICF categories, from all ICF components, were identified in all six units of analysis. Although a number of meaning units were linked to only a few different ICF categories, many meaning units were linked to a wide range of ICF category codes. Below is an example of this:

Table 3. Identified ICF categories in units of analysis.

ICF categories present in six units of analysis n= 19	ICF categories present in five units of analysis n= 10	ICF categories present in four units of analysis n=13	ICF categories present in three units of analysis n= 11	ICF categories present in two units of analysis n=29	ICF categories present in one unit of analysis n=63	Relative frequency of ICF categories in components n=143
Activities & Participation (d)	Activities & Participation (d)	Activities & Participation (d)	Activities & Participation (d)	Activities & Participation (d)	Activities & Participation (d)	Activities & Participation (d)
d115; d310; d350; d3504; d3602; d850; d9205	d110	d3503; d3600; d7203; d910; d9202	d6200; *d7	d2202; d4750; d6504; d710; d730; d740; d7500; d7600; d7603; d7701; d820; d9201	d150; d230; *d3; d3501; d360; d3601; d450; d4503; d4702; d4751; d7400; d7401; d750; d760; d770; d7700; d8451; d860; *d9; d930; d9300	48 (34%)
Environmental factors (e)	Environmental factors (e)	Environmental factors (e)	Environmental factors (e)	Environmental factors (e)	Environmental factors (e)	Environmental factors (e)
e1250; e1251; e250; e2500; e2501; e310; e325; *e4	e1150; e150; *e3; e330; e355	e1151; e1650; e320; e460; e5350	e1200; e2254; e360; e410; e465; e5800	e1501; e1502; e2253; e315; e450; e5802	*e1; e1100; e1350; e2201; e240; e255; e340; e345; e415; e420; e425; e430; *e5; e5450; e5700; e580; e5900	47 (33%)
Body functions (b)	Body functions (b)	Body functions (b)	Body functions (b)	Body functions (b)	Body functions (b)	Body functions (b)
b152; b230	b1300; b2300	b140; b1400; b2351	*b1; b2301; b2401; b28010	b1265; b1560; b2302; b2400; b3400	b1260; b1263; b1266; b130; b1342; b1402; b144; b1600; b1602; b1644; *b2; b2303; b2304; b240; b2404; b280; b2801; b310; b3100; b3101; b320; b330; b7601	39 (27%)
Body structures (s)	Body structures (s)	Body structures (s)	Body structures (s)	Body structures (s)	Body structures (s)	Body structures (s)
s250; s260	s240	-	-	s110; s2500; s2502; s2600	s1106; s2501	9 (6%)

*concepts linked to chapter level only.

Note that only the numeric codes of the ICF categories are presented. Both numeric codes and labels are shown in Appendix 2.

“...Because the speech is my biggest problem...So tiring, you are lip-reading, you are watching people’s faces, trying to recognize sounds, so I’m really totally worn out every day. And I have..., I am a sales manager so [LAUGHING] I’m constantly calling and so on, so its’ really tiring.”

Speech is problematic *d310 Communicating with-receiving-spoken messages*

Lip-reading, looking at someone's face *d3602 Using communication techniques*

Recognize sound *d115 Listening*

Tiring, totally exhausted *b1300 Energy level*

Sales manager *pf (Personal background)*

Constantly calling *d3600 Using telecommunication devices*

A sample of identified categories from the different ICF components will be presented with supplemented statements below.

Activities & Participation (d)

Eight chapters of component (d) were identified. Thirty four percent of all categories belonged to (d). Of these thirty-one percent belonged to *Ch.7 Interpersonal interactions and relationships*, 21% to *Ch.3 Communication*, 15% to *Ch.9 Community, social and civic life*, 11% to *Ch.4 Mobility*, 8% to *Ch.8 Major life areas*, 6% to *Ch.1 Learning and applying knowledge*, and 4% each to *Ch.6 Domestic life* and *Ch.2 General tasks and demands*. Seven categories were recognized in all six units of analysis. Five of these were related directly to oral communication (*d115, d310, d350, d3504, d3602*) while the other two (*d850 Remunerative employment, d9205 Socializing*) represented other kinds of interactions where the hearing loss was considered highly influential. Several informants specifically described

participation restriction (problems experienced in involvement in life situations) in relation to socialization. One woman expressed this issue in the following manner:

“...it affects a lot if you can't hear. Because you can't ... you don't want to go out with people; you don't want to go out to nowhere 'cause you only want to stay in the house on your own and your husband because he knows how it feels...”

Many informants expressed the use of *communication techniques (d3602)* as a solution-focused way of handling communication breakdowns. For example:

“...You know, I have cocktail parties, or everybody is talking, and I don't know what to do, I have to take off my hearing aids and just focus on the lips...”

“..If I deal with ladies [women], like at shops, sometimes I say: "sorry can you please speak up, I can't hear you...”

“...Yes, when I'm in a meeting and I cannot understand people, I do go and sit like this [cups her hands behind her ears]...”

The category *d7203 Interacting according to social rules* was identified in three out of six units of analysis. Mostly, this category was recognized through interpretation of underlying meanings in the meaning units. Often, the informants described interaction difficulties due to misunderstandings or misinterpretations of questions and expressions resulting in humiliating or embarrassing situations for them. One woman explained the following:

“...one of the daily problems, when I meet new people especially [compared to when] I'm talking to people who are used to me, who know my condition..... but if I'm talking to someone new it's like he says 'what's wrong with this one', especially [when it's] in a group...”

Environmental factors (e)

Thirty-three percent of all categories belonged to the (e) component. Twenty-five percent belonged to *Ch.1 Products and technology*, 21% to *Ch.3 Support and relationship*, 19% to *Ch.4 Attitudes*, and 17% each to *Ch.2 Natural environment and human-made changes to environment* and *Ch.5 Services, systems and policies*. Eight categories from the (e) component were identified in all six units of analysis. Five of them belonged to the physical surrounding (*e1250, e1251, e250, e2500, e2501*), while the other three (*e310, e325, e4*) were related to the human and social environment. Sound quality (*e2501*) was often expressed in terms of *external noise*. Several informants described how influential this environmental factor was in their daily lives. For example:

“...when performing a task [at work] in a noisy place and people quickly expect you to do something, and there’s no time to repeat it [the instruction], it looks like I’m a bit incompetent for that job...”

“...well, the hardest thing I think is that you, eh in eh, [when you participate in] large group settings with a lot of background noise around it, yes, I frankly rather stay away from it But I don’t do that, I still go because, yes, eh, I think to myself: I may catch something. Better than nothing. But it staysl hard.”

Hearing aids (*e1251 Assistive technology and products for communication*) were frequently mentioned during the focus groups or the interviews. Mostly, hearing aids were considered as facilitators in daily life and were often considered, from a hearing loss perspective, to be a device that facilitate many of the hearing in daily life situation, and to some, was even considered indispensable..

“..Now, putting the hearing aid on is what gets me through the day, otherwise I can’t hear nothing...”

Several informants also expressed the complex and, for some, emotionally frustrating process of finding a hearing aid that they felt worked out well for them.

“...I found now, what’s become extremely frustrating for me is all the experiments I’ve got to go through to sort of find a hearing aid that actually works. And I’ve never found a hearing aid that connects you to the job [i.e., is working] the way it should be doing, and look that’s quite a, you know, quite a broad claim to be making, you know, against all the technology that’s out there internationally...”

Support from the *immediate family (e310)* was considered highly important in all six units of analysis. The informants often expressed how they could relax and ‘be themselves’ among their loved ones and they indirectly acknowledged this as important support.

“...I thank God for my wife because at the end of the day...you can ask her four times: “What did you say”...”

“...The best part of the day is when I go home and it’s just my husband and, you know, we understand, I can take it out then, my ears relax [laughter]...”

The ICF category *e1650 Financial assets* was identified in four units of analysis. Money seemed to be an issue, often in relation to being able to obtain hearing aids or getting ahold of more advanced hearing aids.

“...I need the hearing [aid] but sometimes I’ve got no money, and maybe my mother has no money to buy [it for me], and then me, I try to come here [public hospital] to get the hearing aid...”

“... [The hearing aid] costs me a fortune, but this is one that has automatic control. It controls volume, tones. So I only put it in my ear and I forget about it...”

Body functions (b)

In all, 27% of the categories belonged to component (b). Four chapters were identified; *Ch.1 Mental functions* (44%), *Ch.2 Sensory function and pain* (38%), *Ch.3 Voice and speech functions* (15%) and *Ch.7 Neuromusculoskeletal and movement-related functions* (3%). The two categories most frequently identified were *b230 Hearing functions* and *b152 Emotional functions*. The feelings most often expressed were negative: frustration, anxiety, unpleasantness, feelings of stupidity, irritation, shame, insecurity, etc. Very few positive emotions were reported by the informants. However, one participant described his/her immediate response upon receiving hearing aids for the first time:

“...well, the first three days you wear them, then you go like, I walked outside like: ‘Oh, how lovely, I can hear the birds. Oh, I hear some noise from the village, how lovely...”

In five units of analysis, *b1300 Energy level* was identified. This was often expressed as tiredness or exhaustion in relation to listening:

“...I fell asleep when I was at the meeting and after they said to me “I know why you fell asleep, because you couldn’t concentrate the whole period...”

“...But if you look at experiences with fatigue in particular, that’s the most important, that you are totally worn out at the end of the day at the age of 35. And I have a profession where I can sit... Totally worn out... Not possible... I cannot keep it up until I’m 67 – that’s just not possible...”

One 4th level category, *b28010 Pain in head and neck*, was identified in three units of analysis. The informants reported headaches, especially, as a consequence of having to concentrate so much on listening.

Body structures (s)

Very few categories of *Body structures* were identified (6%). All belonged to *Ch.1 Structures of the nervous system* or *Ch.2 The eye, ear and related structures*. All categories were related to the hearing system, and most categories belonged to the auditory sensory system (s240, s250, s2500, s2501, s2502, s260, s2600). Two categories were related to the central auditory nervous system, i.e., *s110 Structure of brain* and the more specific 3rd level category code, *s1106 Structure in cranial nerves*. The latter was expressed in a meaning unit as follows:

“...*I think it's the auditory nerve [that's affected]. I think...*”

Not covered

In all units of analysis, the coding ‘e-nc’, appeared. The sub-categorization of this coding revealed that ‘behaviors of others’ (e.g. how other people behaved in communicative situations had impact on functioning with HL) were mentioned in all six units of analysis. An example:

“...*for me it's, when people give, you know, longer sentences, talking longer, then I can eh, get more information [get the gist of the communication partner's message], you know...*”

Examples of concepts coded as ‘not covered’ and not assigned to specific components, are ‘cause of HL’, time aspects, ‘home’ or number of hearing aids.

Discussion

The present study focuses on adult patient perspective on functioning and disability in hearing loss and it part of the ICF Cores sets for Hearing loss project (Danermark et al., 2010). The identification of 143 different ICF categories shows the multifaceted interactions between the categories that constitutes functioning or disability experienced by informants with hearing loss. When asking a person about their experiences with a health condition, the answers are often provided contextually, that is, in *relation* to something or somebody. In the ICF, this

would be referred to as *participation* or *participation restriction* as these concepts are described as the level of functioning in the real environment of a person (WHO, 2001 pp. 14, 15, 16). The latter might thus also explain the large number of environmental factors that were mentioned as facilitators or barriers to hearing loss in this study. From an ICF perspective, the results therefore clearly show that participation and participation restrictions are important in adult HL. This matter has been the target of audiological research to some extent, e.g., in the areas of reducing communication activity limitations and participation restrictions (Hickson et al., 2007; Kramer et al., 2005; Kricos & Holmes, 1996; Kricos et al., 1992) and participation in work (Danermark & Coniavitis Gellerstedt, 2004; Kramer, 2008). The results of the present study further emphasize the importance of investigating external influences, such as environmental factors, when assessing functioning of persons with HL. In addition, the present results highlight the significance of assessing functioning and disability from a multidimensional perspective with tools like the ICF, where both internal and external influences are valued.

Activities & Participation (d)

Eight of the nine life domains described in the (d) component of the ICF framework were identified in this study. Life domains related to interpersonal interaction seem to be especially affected because 52% of the identified categories belonged to *d3 Communication* (21%) and *d7 Interpersonal interactions and relationships* (31%). Most of the categories found in the (d) component are *relational*, i.e., the activity and participation takes place exclusively in relation to other people. The categories *d9205 Socializing* and *d850 Remunerative employment* were identified in all six units of analysis. Even though no relational analysis was made between categories, one can deduce that *d9205* concerns communication and interaction. This is based on the ICF description of the category, ‘engaging in informal or casual gathering with others’ (WHO, 2001 pp. 169), which clearly implies the interaction dimension. The repeatedly

mentioning of experiences that could be linked to the category d850 could largely be attributed to the fact that ‘engaging in all aspects of work’ (WHO, 2001, pp. 165) might require health related activities, such as conversing, that are affected by hearing loss resulting in the activity limitations acting as a mediating factor to the engagement in all aspects of work. Furthermore, ‘work’ also represents a typical setting where execution of a task (activity) or involvement in a life situation (participation) occurs.

Environmental factors (e)

All five chapters of environmental factors (e) were recognized, indicating the relevance of physical, human and social environmental factors in the lives of adults with hearing loss. In line with the instructions of the ICF, (e) categories were investigated as facilitators or barriers in daily life. Some of the (e) categories could be identified as facilitators or barriers, depending on the circumstances. For instance, hearing aids (*e1251*) were viewed as a considerable facilitator in life for many of the informants. This has also been shown in several studies in which benefit and/or satisfaction have been evaluated (e.g. Bertoli et al., 2009; Vesterager, 1990). On the other hand, some informants described financial issues (*e1650 Financial assets*) as barrier in relation to hearing aid use. The impact of personal financial assets on functioning is an area that needs to be fully explored in relation to hearing disability. More recently, Gopinath et al. (2011) investigated incidence and predictors of hearing aid ownership and use among older Australian adults. They found that one key reason for non-ownership of hearing aids was the high costs of aids. According to the authors, hearing aids and services are not included for all in the health care system in Australia. This might also be true for several other countries, resulting in a considerable barrier to hearing aid use.

Noise (*e2501*) was also considered as an important barrier for persons living with hearing loss, both in relation to speech comprehension (d310) and hearing aids (e1251). Noise has been highlighted as an environmental barrier to effective communication in numerous studies.

Great efforts are made in the development of effective noise reduction systems in hearing aids in order to improve this (e.g., Liu et al., 2012; Bentler & Chiou, 2006; Wouters et al., 2002).

Informants also mentioned social support and relationships as environmental factors influencing functioning and disability. The importance of the immediate family was emphasized in all six units of analysis and has also been recognized within the Audiological Rehabilitation (AR) branch as an important source of support in the rehabilitation process of adults with HL (McCarthy & Schau, 2008). Although social support were frequently mentioned by the patients as relevant aspects to functioning with HL measures related to human support and relationship were scarcely identified (Granberg et al., 2014b).

Body functions (b)

Several categories of *Body functions* were identified in the analysis, but at the first ICF level, only three out of eight chapters were covered. Most categories belonged to *Ch. 1 Mental functions* (44%). An important reason for this is the comprehensiveness of Chapter 1. The chapter contains 22 categories, and nine of these were identified. Another reason might be the many third level categories under *b126 Temperament and personality functions*. This category contains ten third level categories, which is rare in the ICF. In the present study, four of these were used in the linking process. Several (b) categories were identified. Besides *b230 Hearing functions*, a wide range of emotions were expressed and linked to the category *b152 Emotional functions*. According to Cieza (2005), ‘other specified’ categories of the ICF should not be used when linking. Hence, when the linking units did not reveal information explicitly named in a corresponding ICF category, the second level category was used instead, with additional information documented. When linking to the category *b152*, a wide range of emotions were documented as additional information. This documentation revealed several negative emotions expressed in relation to living with hearing loss. This finding stresses the importance of acknowledging the emotional impact of hearing loss. From a clinicaõ point of

view negative emotions and appropriate coping strategies could be dealt with through Audiological counseling, a method of guiding patients when adjusting to hearing loss (Clark & English, 2003). Counseling interventions have been explored to some extent, foremost in the area of adjusting to hearing aids, and have demonstrated positive effects on the adjustment process (Abrams et al., 2002; Kramer et al., 2005; Laplante-Lévesque et al., 2006; Saunders & Forsline, 2012). The category *b152 Emotional functions* was identified in all six units of analysis, pointing out its importance and relevance regardless of living context (SA or NL).

The category *Energy level (b1300)* was covered in five units of analysis. Many informants reported that, it required significant effort to listen and to perform necessary mental functions involved in communication such as concentrating, shifting and dividing attention between stimuli. This has also been highlighted in previous and currently scientific work, with a growing interest in the field of *listening effort*. The concept has been explored by several researchers, indicating a clear link between listening effort or cognitive load and speech intelligibility (Fraser et al., 2010; Hicks & Tharpe, 2002; Sarampalis et al., 2009; Kramer et al., 1997; Zekveld et al., 2010).

Body structures (s)

Nine categories from the component *Body structures* were identified in this study and all of these categories were related to the hearing system. The informants were not able to point out any other structures affected by hearing loss. It is a difficult task to ask patients about body structures affected by hearing loss as most informants immediately relate to the *obvious* structures such as outer, middle and inner ear. However, other structures might be affected due to the identified problems related to *body functions*, such as pain in head and neck (*b28010*). Structures related to this were not explicitly mentioned by the informants and therefore not identified in this study.

Strengths and limitations

Settings and informants

A strength of this study is the different settings that were chosen; i.e., two countries that differ substantially (a developed and a developing country). This provided us with patient information from different cultural contexts. SA, as stated previously, has eleven official languages. Despite the inclusion criteria, *conversant in English*, some of the informants spoke poor English and preferred to speak Afrikaans instead. In those cases, an interpreter was used during the interviews (individual interviews). This might be considered a limitation of the study. However, after the interviews, a native Afrikaans speaker listened to the recordings and compared the interpretations made by the interpreter to the statements made by the informants and also checked the transcripts. Only minor corrections were made in the transcripts as a result.

The decision to supplement the focus group with individual interviews for the SA data may be considered a weakness of the study. Questions can arise whether richer or different data would have occurred if the persons were included in the groups in the first place. However, the analysis clearly showed that the individual interviews revealed as rich information as the focus group interviews.

The seven-steps linking procedure

One important procedure to enhance the validity of the present study relates to the analysis method, *the seven-steps linking procedure*. In previous Core Set projects and ICF research projects, the first three steps of the *meaning condensation* methodology as described by Kvale (1996) was used (Boonen et al., 2009; Coenen et al., 2012; Coenen et al., 2011; Glässel et al., 2011; Gradinger et al., 2011). The essence of that method is the condensation part (i.e., shortening of text while preserving the core) of the material until only the meaningful concept remains. Lastly, the meaningful concepts are linked to ICF by using the established linking

rules (Cieza et al., 2002; 2005). However, in examining the present material it became apparent that there was a need for an analysis method that also allowed for interpretations of the underlying meaning of expressions. This matter has also been identified in a previous preparatory study of the project and the rationale for developing this method is further explained here (Granberg et al., 2014b). The summative content analysis (e.g. Hsieh & Shannon, 2005) was used as a broad framework for the analysis. Certain elements, such as the very structured way of analyzing data and the possibility of making latent interpretations, were highly regarded.

The use of an analysis method that revealed both visible and invisible aspects of the text was regarded as a considerable strength in this study.

Conclusions

This study reports on the results of the focus group study in the preparatory phase of developing the ICF Core Sets for Hearing Loss. The data of the current study represent the patient perspectives on dimensions of the ICF framework relevant to adults with HL. In both cultural contexts most of the identified ICF categories belonged to the Activities & Participation component followed by the Environmental factors component. In all units of analysis, specifically aspects of communication and interaction were identified as features important to disability and functioning with hearing loss. Also hearing functions and mostly negative emotions were widely recognized by the informants. Noise, technical aids potentially facilitating hearing, social support and attitudes were considered environmental factors of relevant influence on functioning. The data in the present study support using a multidimensional tool, like the ICF when assessing functioning and disability of adults with hearing loss.

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Supplementary Appendix 1.

The seven-steps linking procedure

Before linking data to the ICF, read and learn about coding data to ICF. This type of information is available in Annex 2 of the classification (WHO, 2001, pp. 219).

1. Identification of meaning unit

A meaning unit is a specific unit of text containing either a few words or a few sentences with a *common theme*. A meaning unit division does not need to follow linguistic grammatical rules; a meaning unit ends when a shift in meaning is detected.

2. Definition of meaningful concept(s)

A meaningful concept is a *condensed part* of the meaning unit that covers a specific topic (condensing means shortening it while preserving the core). Identify the individual meaningful concept(s) of the meaning unit and note these. A meaning unit can contain several meaningful concepts.

3. Interpretation of the underlying meaning (if necessary)

If the text holds a 'deeper' meaning, perform a latent interpretation on the meaningful concept and note this interpretation.

4. Determination of the linking unit(s)

Carefully consider both the meaningful concept and its latent interpretation (if applicable) and note what will be actually linked (i.e. determine the 'linking unit').

5. Deriving the appropriate ICF category, i.e. linking

Use the linking rules by Cieza et al (2002, 2005) and Granberg et al (2014b) to link the linking unit to the suitable ICF category code, and note this category code.

6. Documentation of linking rule applied (if necessary)

If special considerations were needed in the linking process, note what linking rule was applied.

7. Checking the representativeness of the ICF categories

Carefully re-read the meaning unit to see if the identified category codes reflect the essence of the meaning unit. If not, return to step 2.

Supplementary Appendix 2. Numeric codes and labels of identified ICF

(d)	Activities & Participation (n=48)		(e)	Environmental factors (n= 47)	
d110 d115 d150 d2202 d230 d3 d310 d350 d3501 d3503 d3504 d360 d3600 d3601 d3602 d450 d4503 d4702 d4750 d4751 d6200 d6504 d7 d710 d7203 d730 d740 d7400 d7401 d750 d7500 d760 d7600 d7603 d770 d7700 d7701 d820 d8451	Watching Listening Learning to calculate Undertaking multiple tasks independently Carrying out daily routine Communication Communicating with- receiving- spoken messages Conversation Sustaining a conversation Conversing with one person Conversing with many people Using communication devices and techniques Using telecommunication devices Using writing machines Using communication techniques Walking Walking around obstacles Using public motorized transportation Driving human- powered transportation Driving motorized vehicles Shopping Maintaining assistive devices Interpersonal interactions and relationships Basic interpersonal interactions Interacting according to social rules Relating with strangers Formal relationships Relating with persons in authority Relating with subordinates Informal social relationships Informal relationships with friends Family relationships Parent- child relationships Extended family relationships Intimate relationships Romantic relationships Spousal relationships School education Maintaining a job	d850 d860 d9 d910 d9201 d9202 d9205 d930 d9300	Remunerative employment Basic economic transactions Community, social and civic life Community life Sports Arts and culture Socializing Religion and spirituality Organized religion	e1 e1100 e1150 e1151 e1200 e1250 e1251 e1350 e150 e1501 e1502 e1650 e2201 e2253 e2254 e240 e250 e2500 e2501 e255 e3 e310 e315 e320 e325 e330 e340 e345 e355 e360 e4 e410 e415 e420	Products and technology Food General products and technology for personal use in daily living Assistive products and technology for personal use in daily living General products and technology for personal indoor and outdoor mobility and transportation General products and technology for communication Assistive products and technology for communication General products and technology for employment Design, construction and building products and technology of buildings for public use Design, construction and building products and technology for gaining access to facilities inside buildings for public use Design, construction and building products and technology for way finding, path routing and designation of locations in buildings for public use Financial assets Animals Precipitation Wind Light Sound Sound intensity Sound quality Vibration Support and relationships Immediate family Extended family Friends Acquaintances, peers, colleagues, neighbors and community members People in positions of authority Personal care providers and personal assistants Strangers Health professionals Other professionals Attitudes Individual attitudes of immediate family members Individual attitudes of extended family members Individual attitudes of friends

		(b)	Body functions (n=39)	(s)	Body structures (n= 9)
e425	Individual attitudes of acquaintances, peers, colleagues, neighbors and community members	b1	Mental functions	s110	Structure of brain
e430	Individual attitudes of people in positions of authority	b1260	Extraversion	s1106	Structure of cranial nerves
e450	Individual attitudes of health professionals	b1263	Psychic stability	s240	Structure of external ear
e460	Societal attitudes	b1265	Optimism	s250	Structure of middle ear
e465	Social norms, practices and ideologies	b1266	Confidence	s2500	Tympanic membrane
e5	Services, systems and policies	b130	Energy and drive functions	s2501	Eustachian canal
e5350	Communication services	b1300	Energy level	s2502	Ossicles
e5450	Civil protection services	b1342	Maintenance of sleep	s260	Structure of inner ear
e5700	Social security services	b140	Attention functions	s2600	Cochlea
e580	Health services, systems and policies	b1400	Sustaining attention		
e5800	Health services	b1402	Dividing attention		
e5802	Health policies	b144	Memory functions		
e5900	Labour and employment services	b152	Emotional functions		
		b1560	Auditory perception		
		b1600	Pace of thought		
		b1602	Content of thought		
		b1644	Insight		
		b2	Sensory functions and pain		
		b230	Hearing functions		
		b2300	Sound detection		
		b2301	Sound discrimination		
		b2302	Localization of sound source		
		b2303	Lateralization of sound		
		b2304	Speech discrimination		
		b2351	Vestibular function of balance		
		b240	Sensations associated with hearing and vestibular function		
		b2400	Ringling in ears or tinnitus		
		b2401	Dizziness		
		b2404	Irritation in the ear		
		b280	Sensation of pain		
		b2801	Pain in body part		
		b28010	Pain in head and neck		
		b310	Voice functions		
		b3100	Production of voice		
		b3101	Quality of voice		
		b320	Articulation functions		
		b330	Fluency and rhythm of speech functions		
		b3400	Production of notes		
		b7601	Control of complex voluntary movements		