BACKGROUND AND AIMS

Ear and hearing problems can have a major impact on a person’s functioning in daily life. Beyond being able to hear less, ear and hearing problems may lead to limitations in daily activities and restrictions in societal participation\textsuperscript{1-5}. In turn, this may affect one’s psychosocial well-being, cognitive, and emotional functioning\textsuperscript{6-9}. External factors, such as a person’s capacity to cope with challenges and setbacks, influence the functioning of a person as well\textsuperscript{10-12}. For a complete and efficient diagnosis and treatment of persons with ear and hearing problems, it is therefore necessary that not only the auditory functions and structures are evaluated, but that also all relevant aspects of functioning are evaluated. The current approach to diagnosis and treatment of ear and hearing problems differs and depends on the focus and expertise of the care provider(s) and institution(s) involved. It is therefore essential that such a broad approach, in which all relevant aspects are listed in a standardized manner, is applied during the early stage of assessment and diagnosis. Another important reason to broaden the focus to the person’s total functioning is that it can support patient-centred care. Here, the care is no longer organized from the perspective of care providers, but starts from the perspective of the patient. A standard and uniform reference for such an approach is offered by the International Classification of Functioning, Disability and Health (ICF) framework developed by the World Health Organization\textsuperscript{13}. The ICF is based on the biopsychosocial model, where a person’s body functions and structures, activities, participation, and contextual factors (environmental and personal factors) are recognized as important aspects of human functioning and health. Various studies have highlighted the need for such a reference framework in ear and hearing care and recommend the application of the ICF (e.g.,\textsuperscript{14-16}). To make the ICF specific for adults with hearing loss, the ICF Core Sets for Hearing Loss (CSHL) were developed\textsuperscript{14, 17-21}. These are shortlists of ICF categories that are considered most relevant for describing the functioning domains and environmental factors of adults with hearing loss. The Brief CSHL provides a minimal standard for identifying the issues associated with hearing problems and potentially provides a good basis for identifying factors that are relevant in the intake procedure for adult patients with ear and hearing problems visiting an Ear Nose and Throat (ENT) department or an Audiology Clinic (AC).

The overall aim of the work in this thesis was to apply the biopsychosocial perspective of the ICF in the intake of adult patients with ear and hearing problems, by developing and implementing an intake tool based on the Brief CSHL in clinical oto-audiology practice: the ‘ICF-based e-intake tool’. To this end, the Brief CSHL was operationalized into a patient reported outcome measure (PROM). With this intake tool, adults with ear and hearing problems can be screened such that problems and contextual factors relevant to their functioning can be determined and the subsequent care can be tailored to their specific needs. In this thesis, the need for and the creation of the intake tool are described. In addition, it was investigated what is needed to successfully implement the intake tool in clinical practice.
MAIN FINDINGS

Overlap and non-overlap between the CSHL and clinical otology and audiology intake documentation (Chapters 2-3)

In the studies of Chapters 2 and 3, the content of the CSHL were compared with the content of the intake documentation of adult patients enrolling for ear and hearing care at ENT departments and ACs in the Netherlands and the USA. The overlap between the CSHL categories and otology and audiology intake documentation in the Dutch setting was 89% for the Brief CSHL, and 51% for the Comprehensive CSHL (Chapter 2). It is important to note that these percentages do not apply per individual patient record, but apply to all the records of ENT and AC examined together. Various CSHL categories were not found in the intake documentation, including higher mental functions (Body Functions), civic life aspects (Activities and Participation), and support and attitudes of family (Environmental Factors). One extra ICF category emerged from the intake documentation that currently is not part of the CSHL: “sleep functions”. Also some Personal Factors that are currently not included in the ICF classification were found in the intake documentation.

In the USA setting (Chapter 3), the intake documentation of the Mayo Clinic was examined. The Mayo Clinic uses a common medical documentation system (an electronic health record) that is accessible and shared by all providers. In addition to the discipline-specific intake documentation, the system captures patient information recorded by all healthcare providers (referred to as ‘multidisciplinary intake documentation’). The overlap between the CSHL categories and all intake documentation was 100% for the Brief CSHL and 50% for the Comprehensive CSHL. The overlap for audiology and otorhinolaryngology discipline-specific intake documentation was 70% for the Brief CSHL. A lower representation of the Activities and Participation- and Environmental Factors components as compared to Body Functions and Structures was found. Consistent with the results from the Dutch setting, the extra ICF category “sleep functions” was identified, in addition to the ICF category “motor-related functions and activities” (e.g., mobility) and various Personal Factors.

The overall overlap between the CSHL and the intake documentation showed in the two studies supported the CSHLs’ content validity. The partial non-overlap indicates that current intake procedures may not cover all aspects relevant to patients with ear and hearing problems. Furthermore, in both studies different intake documentation methods were identified. Depending on the type of patient, the care provider or department, and the centre, an intake method was applied. These different methods imply differences in the identified topics during the intake procedure. In addition, the identification of the extra categories suggested that the CSHL may need to be expanded in the context of the intake procedure. Based on the findings of these studies, it was concluded that there was a need to develop a practical, systematic intake standard for collecting CSHL information in clinical oto-audiology practice.
Applying the ICF in low vision rehabilitation (Chapter 4)

In the study of Chapter 4, the rehabilitation needs of visually impaired young adults (18–25 years of age) and how these needs relate to the ICF, was investigated. Young adults’ intake documentation from two Dutch low vision Multidisciplinary Rehabilitation Centres (MRC) were linked to the categories of the ICF classification. It was found that most identified rehabilitation needs related to categories from the Activities and Participation component (i.e., linking frequency 67.6%). Most of those needs related to education and work life, running a household independently, self-reliance in mobility, using communication devices and techniques, and psychological consequences of having a visual impairment. Topics relating to interpersonal interactions and relationships and community, social and civic life received little attention in the formulation of rehabilitation needs by visually impaired young adults, although these have been shown to be important in literature. Identified rehabilitation needs in the component Environmental Factors (i.e., linking frequency 21.2%), including support from communication products, stress the importance of including topics on this component in the standard intake procedure as well.

The intake processes within the MRCs were not uniform: rehabilitation needs were obtained from either (1) a semi-structured intake method or (2) a structured intake method via the Participation Activity Inventory (PAI). Although similar ICF categories were identified across the methods, the systematic intake with the PAI resulted in 1) more rehabilitation needs (mean number of 11 vs 3 without the PAI) and 2) a better representation of needs on important domains reported in literature. Therefore, a systematic way of identifying rehabilitation needs seems the preferred method. In conclusion, the findings indicated that there is a need for a suitable survey method that elicits domains relevant to young adults’ lives and development and can be translated into meaningful rehabilitation goals.

In addition to the differences in health domain (ophthalmology versus oto-audiology) there is an important difference between the studies in Chapters 2-3 and Chapter 4 with regard to the phase of care. The first two chapters concern patients who first report with their health care needs, while patients from Chapter 4 concern patients for whom the diagnosis of the functional problem has already been established, with a specific need in the field of rehabilitation. The lessons that can be learned on the basis of Chapter 4 for the development of the intake tool in clinical oto-audiology practice are: 1) the inclusion of aspects of functioning in an intake tool seems to be necessary to ensure relevant patient-needs are identified; 2) the categories that are relevant in the intake depends on the setting and purpose of the intake procedure; 3) the ICF model appears to be a suitable framework for systematically mapping the functioning of individuals.
Operationalisation of ICF Core Set for Hearing Loss into an ICF-based e-intake tool (Chapter 5)

Chapter 5 describes the development process of the ICF-based e-intake tool. This process comprised a mixed methodology: 1) the selection of items from a pool of items of existing validated PROMs, 2) a formal and consensus based decision-making process on the inclusion of items, and 3) qualitative content assessments using an expert survey and a pilot study in patients. The outcome was a disease-specific e-intake tool consisting of 62 items clustered into 6 domains: (1) general information, including reason for visit, socio-demographic and medical background related items; (2) general body functions; (3) ear- and hearing structure and function; (4) activities and participation; (5) environmental factors; and (6) personal factors (mastery and coping). Based on stakeholders’ (i.e., audiologists, ENT surgeons, patient-representatives, and researchers) responses, the instructions of the items of Activities and Participation, and Environmental Factors were adapted such that they explicitly related to patients’ ear and hearing problems. The pilot study showed that the intake tool sufficiently measured what was intended to be measured (content validity). In addition, both stakeholders and patients perceived the intake tool to be relevant and to have a logical and clear structure. Finally, the pilot study resulted in changes to the formulation of the items on environmental factors.

The existing online portal “KLIK” was chosen as the vehicle to implement the intake tool digitally. By using this portal, after completion of the questionnaire, the patient’s outcomes are digitally presented and converted into a “functioning profile”, which is accessible both by the patient and the treating health care professional(s). Further research is recommended to address the ease of reviewing and interpreting the patient’s profile, including the definition of relevant cut-off scores for individual items or domains and the development of a referral decision tree to guide health care professionals on their actions.

Implementation of the ICF-based e-intake tool in clinical otology and audiology practice (Chapters 6-7)

Chapters 6 and 7 describe the studies which focused on the implementation process of the ICF-based e-intake tool. The Behaviour Change Wheel (BCW) framework was used for this, which helps with choosing and designing interventions for behavioural change. This can be a change for both patients (here: completing the intake tool) and for health care professionals (here: using the intake tool). By using the BCW method a theory-informed and systematic approach could be adopted to structure the intervention development process. The BCW is based on a theoretical COM-B model that proposes that for someone to engage in a particular behaviour (B) they must be physically and psychologically capable (C), have the social and physical opportunity (O) to perform the behaviour, and be motivated (M) to perform the behaviour. Using the COM-B model and the more specific Theoretical Domains Framework, firstly, barriers and enablers to using the intake tool perceived by health care professionals and patients were identified and categorized, respectively (Chapter 6).
Focus groups and interviews with health care professionals (ENT surgeons, N = 14; audiologists, N = 8) and patients (N = 18) were performed to this end. Health care professional barriers that emerged included: lack of time to use the intake tool (O) and fear of being held responsible for addressing any emerging problems, even if these would be outside the expertise of the health care professional (M). Health care professional enablers that were identified included: the integration of the intake tool in the electronic patient record (O); the opportunity for the patient to be better prepared for the intake visit (M); and provision of a complete picture of the patient’s functioning via the intake tool (M). Patient barriers included the fear of losing personal contact with the health care professional (M); and the fear that use of the intake tool might negatively affect the conversation with the health care professional (M). Patient enablers included having sufficient knowledge on the aim and relevance of the intake tool (C); the expectation of a better self-preparation for the intake appointment (M); and the expectation of a more focused intake procedure (M).

Secondly, in the study of Chapter 7, an intervention for the implementation of the ICF-based e-intake tool was developed. The development of the intervention was based on the identified barriers and enablers of Chapter 6, and on the available evidence on interventions from other implementation studies. Via a consensus procedure with relevant stakeholders (i.e., health care professionals, an implementation expert, and researchers), a multifaceted intervention was proposed. For health care professionals the provision of educational/training materials and -workshops delivered by opinion leaders (i.e., audiology and ENT staff-members) were suggested. These would need to enhance health care professionals’ knowledge, awareness, skills, and self-efficacy for using the intake tool. Other intervention components included adjustments in the design of the intake tool to facilitate the practical use of the intake tool. For patients, a concise information letter is needed to be sent along with the intake tool. This letter should clarify the goals and relevance of the intake tool, and should address the concerns patients might have regarding the possible negative impact that the intake tool would have on their relationship with the health care professional.

The results of Chapter 7 provide a first step towards the successful implementation of the intake tool. In the next step, this implementation intervention would need to be operationalized into an integrated implementation plan.

**General discussion (Chapter 8)**

Chapter 8 discusses the main findings presented in this thesis. Also, considerations that were experienced in the studies were discussed, and possible implications for clinical practice and future research were outlined. The studies in this thesis showed that current oto-audiology intake standards would need to be adapted to meet the standard of the ICF Brief CSHL. Important developmental steps have been taken towards creating an intake tool (the ICF-based e-intake-tool) that aims to facilitate individualized clinical oto-audiology services from a biopsychosocial perspective. With the tool, patient-centred care can be supported by the
broad view that is presented in a standardized way to health care professionals, prior to intake appointments. Future objectives include the optimization of the content and the use of the intake tool in clinical practice. This will require ongoing training, interactive sessions, as well as reflections on progress and feedback with health care professionals. Moreover, a significant long-term commitment of budget and organizational support is required to accommodate the use of the intake tool. Future research should focus on the further optimization of the intake tool and its actual implementation in clinical practice. Then, the effectiveness of the implementation intervention, and, ultimately, the effectiveness of the intake tool on (the quality of) patient care can be determined.
REFERENCES


