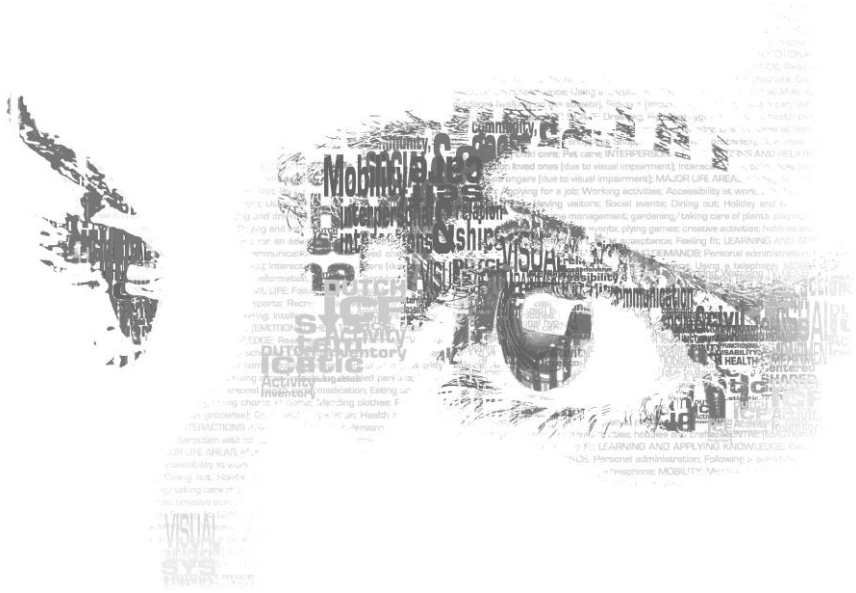
Chapter 10

General Discussion



The aim of the studies described in this thesis was to develop a valid, reliable and feasible tool nested in the International Classification of Functioning, Disability and Health (ICF) framework, to investigate and evaluate the rehabilitation needs of visually impaired adults. To arrive at a tool with these requirements, some important psychometric properties were investigated. Although in a first development not all requirements can be fully assessed and further research is necessary, the Dutch ICF Activity Inventory (D-AI) appears to already have some highly satisfactory psychometric properties. In this General Discussion, the investigation of the psychometric properties of the D-AI is discussed, the strengths, limitations and clinical implications of the studies are addressed, and suggestions are made for future research.

Validity

With regard to the psychometric properties, an important factor is 'validity', which can be defined as "*the degree to which an instrument truly measures the construct(s) it purports to measure*".[1;2] As rehabilitation needs are often expressed at the level of activities and participation, the D-AI measures these needs of visually impaired adults in the ICF context where 'Activity and Participation' domains are formulated.[3] In addition, a key to delivering personalized care in rehabilitation medicine is to investigate needs from the patient's perspective. The concept of the D-AI is promising as the possible rehabilitation needs are actually investigated from the patient's perspective. This was recognized by the professional intakers who agreed that, as the aim of rehabilitation is to improve the patient's quality of life, it is important to have an unbiased overview of the needs of the patient from his/her own perspective at the Activity and Participation level. With the D-AI it is possible to avoid that only a selection of the needs is investigated due to, for example, the personal preferences of the intaker. Moreover, with the broad overview of possible needs assessed with the D-AI in a structured and standardized way, a patient-centered approach seems to be better guaranteed, thus providing more valid information. The D-AI can be seen as a good example of 'patient-centeredness' which is still seen as an important paradigm in medicine and the social sciences'.[4-10]

Furthermore, the validation process of measurement instruments determines whether there are grounds to believe that the content of the instrument actually measures what it was intended to measure. Different research strategies can be used to assess different types of validity (e.g., face and content validity, construct validity, longitudinal validity[2]). The amount evidence emerging from these strategies accumulates to the degree of validity of an instrument in a specific context and population. With respect to the D-AI,

some types of validity were addressed more thoroughly than others. The first, and perhaps the most important, is content validity (including face validity) which is related to the relevance and comprehensiveness of the items.[11] Content validity refers to "… *the degree of which a health-related patient-reported outcome instrument is an adequate reflection of the construct to be measured*" whereas face validity refers to ".. *the degree to which (the items of) a health-related patient-reported outcome instrument indeed looks as though they are an adequate reflection of the construct to be measured"*.[1]

Face and content validity

A strength in the developmental process of the D-AI was the collection of items that were applicable to the target population. As the content of the original Activity Inventory (AI) was initially developed in the USA, the first step in the developmental process of the D-AI was to translate the original AI into Dutch. However, as expected,[2] substantial cross-cultural differences still existed, indicating a lack of face and content validity for the Dutch situation. Since the use of qualitative techniques in the target population is considered to increase face and content validity,[12] an important step in the developmental process of the D-AI was to collect a useful set of items, based on focus group discussions with visually impaired persons and with rehabilitation experts. To further increase the validity, efforts were made to include patients with different characteristics and experts from different disciplines in rehabilitation. The focus group discussions were conducted until the input was confirmatory. A feasibility study confirmed that no topics were overlooked, and patient files revealed no rehabilitation needs/items that were not available in the D-AI. These findings support the conclusion that the D-AI has a high face and content validity. However, its extensiveness made the D-AI less feasible and highlighted the need to shorten the questionnaire.

Construct validity

As there is no gold standard available, construct validity can be used to provide evidence of validity. Construct validity is related to the degree to which the scores of a measurement instrument are consistent with hypotheses;[1] for example, with regard to differences between relevant groups or scores of other instruments (by testing hypotheses), and to internal relationships (structural validity). To gain insight into the constructs being measured in the D-AI, factor analyses were performed and correlations with similar constructs were determined.

Structural validity: factor structure of goals

In contrast to Massof et al., who performed factor analyses on all tasks (underlying all goals),[13] in this thesis, separate factor analyses were performed on tasks underlying several goals. It is useful to treat every list of tasks underlying goals as separate measurement instruments, as this will better reflect how the D-AI will be used by the Multidisciplinary Rehabilitation Centers (MRCs) for visually impaired persons in clinical practice. In this way, for each patient a specific selection of goals can easily be assessed and interpreted at the task level. Information at the goal level provides insight into the needs of the patient to be able to better participate in society. In addition, information at the task level may be helpful in creating a specific rehabilitation plan, as this provides insight into what aspects must be tackled to be able to perform the umbrella goal. Although confirmatory factor analyses can be seen as more appropriate for validation purposes (as a priori hypotheses about dimensions of the construct can be tested),[2] this was not favorable in this developmental phase of the D-AI. The content of the AI was not only translated but also considerably adapted and assessed in a new patient population.[14] Moreover, because every list of tasks underlying goals was seen as a separate measurement instrument, there was no clear idea about the number and types of dimensions in the new D-AI.

Consensus discussions occasionally revealed that (despite that factor analyses indicated so) a specific task could not be removed from the D-AI because it was essential to be able to perform this task to perform the umbrella goal, or because many people reported this task to be very difficult and indicated the need for rehabilitation on this specific task. In light of what the instrument purports to measure, it was essential to develop a feasible instrument which can be used to investigate a broad range of individual rehabilitation needs, and to create an individual rehabilitation plan. Therefore, developing an instrument with only strong psychometric properties was seen as having minor importance, so that some items were not released from the D-AI. Items within the same scale that appeared to form a factor can be thought of as a reflective model of an underlying construct, meaning that all items in the model are a manifestation of the same underlying construct.[1;2;15] Although the umbrella goal may also be a manifestation of this construct, additional items may contribute to reaching the umbrella goal. Therefore, many goals should be interpreted as a formative model, meaning that the difficulty of underlying items ‘form’ or ‘cause’ the difficulty of the umbrella goal.[16] This also means that the association between difficulty scores of goals and underlying tasks is not necessarily a strong one.

Hypothesis testing: correlations with similar constructs.

For the goals in the domains 1 (i.e., 'Learning and applying knowledge') and domain 2 (i.e., 'Coping with mental (emotional) health aspects'), construct validity was globally investigated by testing correlations between goals and underlying tasks (representing one construct) and similar measures. Spearman correlation coefficients were used to measure the strength of the associations at baseline between the D-AI measures and similar constructs. As expected, results indicated that the difficulty of all three goals in domain 1 (i.e., 'Reading', 'Writing', and 'Watching TV') showed a strong correlation with the most related (sub)scales of the Low Vision Quality Of Life questionnaire (LVQOL) (i.e., 'Reading small print', 'Visual motor skills', and 'Basic aspects', respectively). In addition, associations between the goals in domain 10 (i.e., domain 'Coping with mental (emotional) health aspects'; goals: 'Handle feelings', 'Acceptance', and 'Feeling fit') and related constructs (i.e., depression, adaptation to vision loss, and (physical) fatigue, respectively) revealed a strong association between 'Feeling fit' and (physical) fatigue and supported merging the goals 'Handle feelings' and 'Acceptance' into one goal 'Emotional life' as was also suggested earlier based on feedback from assessors and patients. These associations provided better insight into the constructs being measured by the D-AI; however, as the number of challenging and specific a priori hypotheses was limited, the evidence gathered for construct validity was restricted. For instance, analyses for domain 1 revealed (as expected) strong correlations, but many other correlations were also strong. As the goals and underlying tasks in this domain partly rely on a similar aspect of visual functioning (e.g., 'visual acuity') this is not surprising. Therefore, future studies may focus on other hypotheses testing convergent, divergent, and discriminative validity. It may, for example, be useful to test hypotheses about differences between persons with various types of eye conditions, differences in visual functioning (e.g., problems with near vs. distance vision, central vs. peripheral sight loss, or degree of visual acuity), several co-morbid conditions, and age groups. Moreover, better insight in the construct validity of goals in other domains will be useful.

Measuring change over time

As the purpose of the D-AI is not only to investigate but also to evaluate rehabilitation needs over time, it is necessary to investigate to what extent the instrument is responsive to change in the concept to be measured. This can be seen as an aspect of validity in a longitudinal context and is often described as responsiveness, which can be defined as "*the ability of an instrument to detect change over time in the construct being measured*".[1;2;15] To test whether an

instrument is able to detect changes, it should be expected that at least a proportion of the patients would improve or deteriorate in the construct to be measured. During the course of rehabilitation, because there are specific interventions (e.g., prescribing optical aids) to reach the goals in domain 1 (i.e., 'Reading', 'Writing', and 'Watching TV'), it is plausible to assume that patients who received these interventions would in fact improve. However, for other goals, such as those in domain 10 (i.e., 'Handle feelings', 'Acceptance', and 'Feeling fit'), this is less obvious.

Difficulty of goals over time

As a first step to better understand the longitudinal interpretation of the D-AI difficulty scores, longitudinal changes were globally investigated more thoroughly for the goals in domain 1 and domain 10; these changes were qualitatively compared to changes in similar or related constructs. An interesting finding for the goals in domain 1 was that the outcomes of the LVQOL were influenced to a greater extent by other variables, such as depression. The goals in the D-AI may reflect more narrow constructs, which can be an advantage in evaluating the effectiveness of specific interventions in reaching rehabilitation goals. In addition, the D-AI difficulty scores in this domain showed a greater change over time, which may indicate that difficulty scores were more responsive compared to the scales of the LVQOL. However, it cannot be ruled out that LVQOL scores represent the more robust scores over time and that the D-AI is more sensitive to measurement error. For domain 10, none of the goals and underlying tasks improved over time (after correcting for confounding variables), except for perceived difficulty of the goal 'Acceptance'. Related constructs (measured with additional questionnaires) also stayed unchanged, except for (physical) fatigue which decreased between baseline and the 4-month follow-up. However, feedback from assessors indicated that the formulations of the goals in domain 10 were not clear. Therefore, these were rephrased (i.e., for 'Feeling fatigue') or replaced (i.e., 'Emotional life' instead of 'Handle feelings' and 'Acceptance'). Consequently, the ability to measure change over time should be further investigated for the newly formulated goals, as well as for the goals in the other domains of the D-AI.

There are some important limitations in the analyses applied to evaluate the longitudinal interpretation of the D-AI. In assessing the responsiveness, it is recommended to test specific hypotheses about expected relationships between changes on the instrument under study and changes on other instruments that measure similar or different constructs.[1;2;15] However, in formulating hypotheses, detailed knowledge of the construct that is intended to be measured, and a

theory to hypothesize the relation is needed. Because available related questionnaires intend to measure slightly different concepts, and a precise insight in the construct that was being measured using the D-AI was not yet available, it did not seem appropriate to formulate specific hypotheses concerning the relation of the D-AI and related measures to validate the responsiveness. Therefore, the results should be interpreted with caution. Nevertheless, studying the similarity in change over time in the same study population did provide better insight into the constructs being measured. Formulating more specific hypotheses about expected differences between subgroups before and after a specific rehabilitation program, may further contribute to the degree of longitudinal validity of the D-AI. However, care should be taken in formulating these a priori hypotheses. Because the effect size of rehabilitation is still unknown, it is not yet possible to assess the responsiveness of the D-AI based on the same effect size. Another possibility to further investigate the responsiveness is to use a transition question (e.g., "Compared to 1 year ago, how would you rate 'reading ability' ": 'somewhat/much worse', 'similar' or 'somewhat/much better'). However, since these questions are not yet validated, critique has been formulated,[17;18] Mokkink et al. recommended to formulate hypotheses about expected relations with a transition question.[19] Moreover, another alternative may be to investigate item or scale invariance over time using modern psychometric techniques.[20]

Importance of goals over time

Based on detailed analyses in domain 1 and 10, it appeared that the opinion on what is of value for a particular patient (expressed by goal importance scores) remained relatively stable over time. However, longitudinal analyses for some other domains revealed that importance scores changed over time for only some goals (not corrected for confounding variables). A possible explanation for these changes may be that, as a result of rehabilitation, the patient is able to participate more in society, making other goals either more relevant or less relevant. For assessing needs, and composing or adjusting a rehabilitation plan, the importance or relevance of goals should be considered. However, to evaluate the effectiveness of a specific rehabilitation intervention, a recurrent assessment of importance questions may not be useful. This implies that there is no need to further investigate the responsiveness of importance questions.

Reliability

In addition to 'validity', another important psychometric property for measurement instruments is 'reliability' which can be defined as "…*the degree to which the measurement is free from measurement error*". [1;2;15] More specifically, it can be described as "…*the extent to which scores for patients who have not changed are the same for repeated measurement under several conditions*". Although the concept of ´reliability´ is essentially different from ´validity´, a reliable measure is necessary to enable a valid measurement.

Test-retest reliability

For most goals, the Cohen's (weighed) kappa for goal importance and difficulty was moderate to almost perfect. However, for some goals, test-retest reliability was not sufficient. In order to improve the test-retest reliability, for the newly developed D-AI, the exact formulation of 23 (48%) goals (plus 4 sub-goals) was (slightly) rephrased based on the kappa values, the observed agreement, and the available feedback. As these formulations were changed, test-retest reliability should be investigated for these new formulated goals. In addition, future studies should also investigate the test-retest reliability for underlying tasks. Due to the routing structure, the current sample size was too small for this purpose. Moreover, the current study was not designed to investigate other types of reliability, such as inter-rater reliability (reliability between two different assessors) or reliability for and between different types of assessment (e.g., written, by telephone, face-to-face, via internet). This may be useful for future applications of the D-AI.

Internal consistency of tasks scales underlying goals

Compared to individual tasks, a scale of several items usually allows for a more reliable and stable measure. As a measure of reliability for tasks within a factor structure, the internal consistency (i.e., "*the degree among interrelatedness of the items*" [1;2;15;21]) was investigated by means of the Cronbach's alpha. However, due to the routing structure and the response category 'not applicable', the current sample size was not sufficient to determine the internal consistency for all (sub)scales. Therefore, the internal consistency of (sub)scales needs to be further investigated.

Feasibility and interpretability

In addition to measurement properties such as (longitudinal) validity and reliability, interpretability is an important requirement for the suitability of an

instrument in clinical practice or research. Although it is not considered a measurement property,[2] to implement a new intake method it is essential to evaluate and optimize the interpretability. Interpretability can be defined as "…*the degree to which one can assign qualitative meaning – that is, clinical or commonly understood connotations – to an instrument's quantitative scores or change in scores*".[1;2;21] In addition, better interpretability will probably also improve the feasibility.

Formulation understanding

In developing a questionnaire, it is essential that the formulation of questions is carefully chosen to avoid influencing an informant's response. Therefore, an attempt was made not to formulate 'double-barreled' questions, ambiguous terms, negative wordings, value-laden and leading questions.[22] The interpretation of questions by patients and assessors was evaluated and revealed that some questions needed rephrasing to improve their clarity. However, questions were not systematically evaluated one by one together with patients; to further improve the newest version of the D-AI this would be useful.

Response categories

The pilot study in the developmental phase revealed that the response option 'not applicable' for the question on goal importance had to be added (similar to the difficulty questions), as the study revealed that the response category 'not important' did not always reflect how the patient felt about a topic. A drawback is that this may reflect several answers, making interpretation of the meaning of 'not applicable' unsure. The patient may not have been able to make up his mind or may never have performed the activity. However, it is also possible that the patient is no longer able to do the activity due to comorbidity, or that the patient is usually assisted. A ´not applicable´ answer might also ignore the relevance of not performing the activity. Imagine a patient who has enrolled in the MRC because he needs advice about buying and using a computer for personal correspondence; this patient may score the difficulty of ´Using a computer´ as ´not applicable´ because he does not yet have a computer. This emphasizes that the reason for responding 'not applicable' should be considered in creating a rehabilitation plan.

Investigating rehabilitation needs and the meaning of scores

Interpretation of the priority score

To investigate rehabilitation needs, the D-AI rates the perceived importance (not important [0]; slightly important [1]; moderately important [2]; very important [3]; 'not applicable') and the perceived difficulty (not difficult [0]; slightly difficult [1]; moderately difficult [2]; very difficult [3]; impossible [4]; 'not applicable') of possible rehabilitation goals. Subsequently, 'priority scores' were calculated as the product of the ordinal importance and difficulty ratings for the goal, which is the method used in "Goal Attainment Scaling", to weight difficulty with value,[23] to define goals with possible rehabilitation needs. However, as no gold standard is available (i.e., criterion validity could not be assessed) and as patients were not asked to rank order the priorities of the rated goals, there is no way of validating the priority score which should be monotonic with the patient's rank scores. Therefore, it can be questioned whether the exact priority score that was calculated by the importance and difficulty of a goal actually is a valid representation of a rehabilitation demand. It was assumed that goals which are possibly relevant for rehabilitation are, to some degree, important and difficult (i.e., at least 'a little important/difficult'), resulting in a priority score ≥ 1. This was used for the analysis in which rehabilitation needs recognized by the D-AI were compared with those recognized by the usual unstructured intake. However, care should be taken in the interpretation of the exact priority scores in choosing rehabilitation goals (e.g., when using only top-priority scores for assessing underlying tasks as was done in the large validation study). As was the case for difficulty scores,[24] respondents may not be able to differentiate between the numerous response categories that result from multiplying the importance and difficulty rating scales. Moreover, since the meaning of ´not applicable´ is multi-interpretable, there is a chance that for rehabilitation potentially relevant goals were missed because the goals did not result in a priority score. This highlights the importance to discuss rehabilitation needs as input for a feedback conversation in light of the ICF framework, with the intaker and patient together.

Interpretation of difficulty scores

Concerning the interpretation of difficulty scores, it could be reasoned that importance is inherently incorporated into difficulty ratings as patients may not be able to rate impairment or difficulty without including the importance of the particular activity to them. Therefore, patients might overestimate the importance of goals that they now find difficult to accomplish or, conversely, undervalue goals that they can no longer achieve. However, the low correlations between

value of independence (i.e., importance scores) and visual ability (i.e., difficulty scores), confirm the conclusion of Massof et al. that these two latent parameters can be treated as if they are statistically independent.[25] Nevertheless, these correlations may be subject to bias as, due to the routing structure, correlations could only be assessed for goals that were of at least ´some importance´.

Interpretation of importance scores

Concerning the interpretation of the importance scores, the study revealed that the interpretation of the goal importance questions seemed to be more variable compared to goal difficulty questions. It was therefore suggested that it might be valuable to change the exact formulation of the goal importance questions into "How important is it for you to include [goal] in the rehabilitation plan", after discussing the possibilities of rehabilitation for difficult goals in light of the ICF scheme, thus only assessing difficulty scores in the D-AI-1. This approach will be evaluated as MRCs are currently only assessing goal difficulty questions as input for a shared decision-making process. On the other hand, to maintain a more objective investigation of the patient's personal preferences immediately after enrolment, and to better guarantee that personal factors (being part of the ICF framework) are investigated, it was later discussed that it may be useful to assess the importance of goals, but only by rating 'important' or 'not important' instead of using exact scores. Then, the next step will be to discuss the relevance of taking up a particular goal (of 'importance'/'relevance' and at least some difficulty) in light of the complete ICF framework, to create a rehabilitation plan. Nevertheless, for research purposes, scoring the importance and difficulty may be used as a measure to assess quality of life or participation of visually impaired persons, in which a reference to the performance, as well as the relevance is needed.[26;27]

Creating a rehabilitation plan using the D-AI in a shared decision-making process

Investigating needs from the patient's perspective

Studying the files of the patients in the pilot study in the developmental phase, revealed that only 43.4% of the rehabilitation needs that emerged during the entire rehabilitation program were recognized in the first phase of the usual intake (i.e., telephone interview and visual function examination), which indicates that many rehabilitation needs were identified during the course of rehabilitation. Moreover, in the usual (unstructured) intake, it was not clear whether needs were actually investigated from the patient's perspective. This increases the risk that

the rehabilitation services are driven by supply and not by the demand of the client. Subsequently, it may hamper shared decision-making about the rehabilitation program that needs to be followed. This supports the use of the D-AI as this facilitates a complete overview of possible rehabilitation needs from the patient's perspective, from the very beginning.

Discussing needs in light of the ICF framework to select rehabilitation goals

With the D-AI, an extensive overview of possible rehabilitation needs (i.e., list of goal scores, e.g., hierarchically ordered from higher to lower scores) may be produced, making it a challenge to focus on the most relevant needs for rehabilitation. It was concluded that, after assessing the D-AI, the next step in the intake procedure has to be a feedback conversation between the patient and the rehabilitation expert in which the actual rehabilitation plan is discussed in a shared decision-making process. The outcomes of the D-AI may serve as input at the Activity and Participation level for a structured conversation between patient and professional to facilitate a more structured medical communication in ICF terms. As input for this conversation, it is not only necessary to investigate the self-reported 'performance' in real life at the Activity and Participation level[3] (i.e., by administering the difficulty of goals in the D-AI), but also to test the remaining (visual) functions (i.e., 'body functions and structures' in the ICF framework). This will provide insight in the 'capacity' at the Activity and Participation level of the patient to allow to find an appropriate intervention.[3] Also, the other components of the ICF model have to be taken into account: health status and contextual factors (i.e., external factors, personal factors) as these components may impact on the difficulty and importance (rated by the patient) of a specific goal and on whether a goal will be part of the actual rehabilitation plan. Nevertheless, as discussed above, the importance of the goal itself can be different from the relevance to include this goal in the rehabilitation plan. Therefore, the patient has to be informed by the rehabilitation professional which possible rehabilitation interventions belong to potential relevant goals; knowing the specific content of each possible intervention and what can be expected as a result (for a specific individual) may guide/help the patient and professional to formulate the actual rehabilitation plan. For example, after realizing that being able to do the "Daily shopping" would encompass a complex and intense rehabilitation trajectory, and that what can be expected as a result of this is low, the patient may prefer to focus on another (e.g., less important) goal which is easier to accomplish. Therefore, which 'rehabilitation products' belong to specific problems[28] should also be taken into consideration. In summary, the relevance of taking up a particular goal in the rehabilitation plan should still be discussed in

light of the ICF framework. The exact steps in this shared decision-making process should be further investigated. It is generally thought that shared decision-making is important in providing patient-centered care[29] and to improve the effect of rehabilitation for chronic impairments with multiple sessions.[30] Therefore, this plan must be made by the patient and professional together. In this process, rehabilitation professionals should be careful not to impose their own assumptions and values. It is the job of the rehabilitation professional (e.g., intaker) to fully inform the patient about all possibilities and expectations, so that the patient can make a well-balanced choice. For example, rehabilitation professionals should report for each goal why it was decided that this will (or will not) be part of the rehabilitation plan, to justify the choices made and to better guarantee that this process is patient-centered.

Value of the D-AI for evaluation purposes

In this thesis it was discussed how the concept of the D-AI can be used for an individual patient to clarify needs and to compose a rehabilitation plan. In addition, assessing the D-AI immediately after enrolment is not only useful in setting individual rehabilitation goals, but also provides a baseline measurement so that the effect of rehabilitation for individual goals can be determined using the same instrument, which is important for monitoring the individual patient. An effective intervention is expected to decrease the difficulty to reach the goal. Moreover, the D-AI can also be used to provide information at the group level to evaluate factors that lead to the success or failure of different rehabilitation programs. Assessing the D-AI as part of a standard and structured intake process enables MRCs, as well as insurance companies and policymakers, to have better insight into the needs of different patient groups. In addition, another important advantage of the D-AI is that a more structured intake makes evaluation of rehabilitation programs more feasible. Recurrent assessment of difficulty scores of the D-AI enables to evaluate and improve rehabilitation programs for better evidence-based practice. Recently, Burggraaff et al. evaluated the effectiveness of a training protocol for the use of closed-circuit television by visually impaired adults using the D-AI (and other outcome measures) and concluded that this training was not more effective than self-practice with the device without standard training.[31;32] A better insight in the effects of specific rehabilitation interventions may result in a better rehabilitation outline, so that visually impaired persons will improve their visual ability which may lead to faster/increased independence and participation in society. More randomized clinical trials are needed to provide additional evidence for different rehabilitation programs.

However, for a better use of the D-AI for evaluation purposes, more information is needed about the interpretation of scores. For example, even a significant difference or change is not necessarily clinically relevant. The minimally clinically important difference can be defined as "…*the smallest difference in score in the domain of interest which patients perceive as beneficial and which would mandate, in the absence of troublesome side-effects and excessive costs, a change in patient management*"[33] and a similar meaning can be applied to a minimally important change: the smallest change in score in the construct to be measured which patients perceive as important.[11;15] As the studies performed in the thesis did not focus on the interpretation of difference or change scores between or within persons, respectively, future studies should focus on these topics to improve the interpretability of the scores in the D-AI on these aspects.

The role of the importance score for evaluative purposes was also investigated; in contrast to the results presented in the main study, the implementation study revealed that importance scores of some goals may change during the course of rehabilitation. However, it is not possible to state, in general, whether an increase or decrease in importance is a positive or negative outcome of rehabilitation, as it largely depends on personal and external factors. Therefore, although asking whether a potential rehabilitation goal is of 'importance' is of particular use for the purpose of investigating rehabilitation needs in a structured way after enrolment, the importance may not be a useful evaluation question for measuring the effectiveness of a specific rehabilitation program or trajectory.

Limitations of the study and recommendations for further implementation and research

Limitations

The most important aim of this thesis was to develop a valid, reliable and feasible tool nested in the ICF framework to investigate and evaluate rehabilitation needs of visually impaired persons. Second, this new tool was planned to be used to investigate rehabilitation needs of visually impaired persons entering an MRC and to evaluate these needs over time. As the basis for the planned instrument was already available (i.e., the AI), reaching these two aims seemed realistic. However, improving and adapting the available questionnaire to make it applicable to the Dutch situation entailed much more work than was expected. In fact, the work presented in this thesis should be seen as a work in progress;

some properties of the D-AI have not yet been addressed and the new D-AI has not yet been used in new validation studies using models based on, for example, Item Response Theory (IRT).

Study design

To achieve the second aim of this thesis, recurrent assessments of rehabilitation needs were applied (i.e., 4 and 12 months after baseline). However, to investigate the change in rehabilitation needs over time, a measurement tool with strong psychometric properties is needed. However, baseline analyses to investigate and improve the validity, reliability and feasibility were performed during the data collection of the follow-up measurements. Although some adaptations could be applied on future the analyses (e.g., omission of some items), a part of the adaptations to the D-AI could not be applied in the data collection at baseline and follow-up measurements (e.g., additional or rephrased items). Retrospectively, for the validation process it may have been better if only baseline measurements had been performed, but in a larger sample size. In addition, for validation purposes it may have been better not to apply a routing structure so that the difficulty of all goals and underlying tasks (or a set of tasks to increase the feasibility) could be used in the analyses. This would have enabled a better evaluation of the psychometric properties of the goals and tasks within the D-AI (e.g., analysis of the factor structure of all goals and applying analyses based on IRT).

On the other hand, MRCs wanted to have some impression about how rehabilitation needs change over time. Data from the current study are a first step for MRCs to provide a more objective insight into the needs of visually impaired patients at baseline. Moreover, although longitudinal validity of an instrument and effect measurements cannot be investigated with the same instrument in the same study, data from the current observational study are a first step to collecting more objective information over time.

Study population

Examining the characteristics of the participants, it appeared that some had a relatively good visual acuity. This may be a result of applying the Dutch guideline on the referral of visually impaired persons to low vision services[34-36] which states that patients can be referred when vision-related problems in daily life cannot be addressed by interventions in standard ophthalmic care, but can potentially be solved by visual rehabilitation. In addition, it is possible that some patients who enrolled at the MRC (perhaps on their own initiative) did not to meet the criteria for rehabilitation. Therefore, some of the patients may not have received

rehabilitation (e.g., in 13 patient files it was not clear whether the patient actually received any rehabilitation or advice). Also, as assessment of the D-AI was performed in addition to the usual intake, not all patients that were contacted agreed to participate in the study. This recruitment process may imply selection of a subgroup of visually impaired persons that are, for instance, healthier and less depressed, which may influence the rehabilitation needs identified and the effect of rehabilitation. Finally, although most participants who are referred by the ophthalmologist probably also contact the MRC for enrolment by themselves, this is not necessarily the case. For ethical considerations, the MRCs decided not to ask participants who did not contact the MRC by themselves to participate in the current study, as these patients were potentially unaware of their enrolment at the time of recruitment. Although these patients were later approached by the MRC to assess their needs in the usual intake, they were not asked to participate in the current study.

Recommendations for implementation and future research

The research team was involved in initiating an implementation process. However, as implementation experiences revealed, it is recommended that MRCs continue to involve the developers to regulate any future adaptations. This is important because applying changes to the D-AI not only influences its feasibility, but also its validity, reliability and interpretation. The D-AI should be evaluated on these aspects from different clinical perspectives (e.g., intakers, policymakers, patients) as well as from a theoretical perspective (e.g., researchers). This will prevent making adjustments to the D-AI without fully knowing the effects. For instance, decreasing the number of response categories of task difficulty questions (i.e., only ‘not difficulty’ or ‘difficult’ as is currently being tested by Bartiméus), also influences the sensitivity and responsiveness of the D-AI-2 and probably makes the D-AI less effective for evaluation purposes. Therefore, on-going communication and collaboration between practice and research is needed to further improve the validity, reliability, interpretability and feasibility of the new D-AI.

Future improvements in using the D-AI

The MRCs have already made improvements in structuring their intake by using the D-AI. However, based on the results of the work in this thesis, several recommendations can be made with regard to further implementation. As discussed earlier, it is recommend to train intakers in how to administer the D-AI in a neutral and objective way, to guarantee assessment from the patient’s perspective, and to enhance the reliability of the D-AI. In addition, it is

recommended to incorporate an enforcement to answer each question, which decreases the risk that intakers (consciously or unconsciously) still only focus on a selection of goals. Moreover, continuous evaluation of the use of the D-AI in daily practice is important.

At this moment, MRCs are gaining considerable experience in using the D-AI which can be used to optimize the structured approach of discussing needs in light of the ICF scheme to create the rehabilitation plan. The D-AI-2, for example, is very informative in understanding the limitations in activities that cause restrictions in participation. A better understanding of these restrictions for an individual by means of assessing the D-AI-2 may be necessary to discuss the possibilities for rehabilitation. However, it may not be feasible to assess the D-AI-2 for all goals that are potentially relevant (i.e., the number of goals may be too high). Once more intakers have used the D-AI-2 in daily practice, their experiences should be exchanged and evaluated. This may lead to a consensus for a more specific protocol of the feedback conversation and the place of the D-AI-2 in the intake process. As discussed previously, this process should not only focus on the needs at the activity and participation level but also on other concepts of the ICF framework, as the most successful rehabilitation plan depends on understanding the interaction of target problems, health characteristics (e.g., eye condition, co-mobidity) with corresponding impaired body function and structures (e.g., visual functioning), and contextual factors (i.e., personal and environmental) which improve or deteriorate them.[37] Although MRCs already collect relevant information about the other concepts, it is recommended to develop a structured approach. To improve this process, a patient-centered communication strategy may be developed in which the rehabilitation professional (e.g., the intaker) integrates all relevant patient information into a well-targeted rehabilitation strategy for an individual visually impaired patient. For the communication strategy, models such as motivational interviewing[38] and shared decision-making may be used,[39-41] including a decision-support tool to facilitate the process of interacting with the patient to arrive at an informed, value-based choice between different treatment options.[42] The WHO have developed several ICF tools (i.e., the ICF Assessment Sheet; ICF categorical Profile; ICF Intervention Table; ICF Evaluation Display) that may be helpful in rehabilitation management to support the understanding and facilitate the description of functioning and disability, and to improve the planning and evaluation of rehabilitation.[28] These tools may also be useful to design a feasible (digital) environment for a proper documentation.

Transparency

In order to further increase the transparency of the intake process and the creation of a rehabilitation plan, it is essential to carefully define the shared decision-making process and to explain the choices for rehabilitation that were made. As mentioned, it is important to incorporate this in the software of the D-AI or the patient information system. It should be clear for each goal why it is or is not part of the rehabilitation plan. Linking possible rehabilitation products to underlying tasks (i.e., MRCs have started this process) is a first step. A proper documentation of these factors and the decisions in this process will further increase transparency of the rehabilitation process. Moreover, this will enable longitudinal prognostic studies on the factors related to functioning and health in persons with a visual impairment. This also highlights the need for a proper documentation of the content of the rehabilitation plan as this will enable MRCs to better evaluate the effect of specific rehabilitation interventions. The studies in this thesis revealed that this information was often lacking in the patient files.

Validating several assessment modes

To further increase the feasibility, it is recommend to develop and validate other administration modes for the D-AI. It is, for example, important to keep in mind that even (older) adults with a visual impairment increasingly make use of the internet. In the Netherlands, internet use among adults in the general population up to age 65 years is almost 100%.[43] Therefore, it will be important to validate an internet version of the D-AI (i.e., in which patients can assess the D-AI by themselves (or with help from a significant other) at the computer), as it is known that biasing influences may exist between different types of administration (e.g.,[44-45]). An internet version of the D-AI will enable an even more efficient intake process (i.e., the D-AI-1 and even D-AI-2 may already be assessed before enrolment). Moreover, in more complex situations (e.g., patients with dual sensory loss) a face-to-face interview may be favorable and should therefore also be validated. Finally, in case of vulnerable patients (e.g., some patients will be unable to assess the D-AI by themselves due to, for example, dementia), a significant other (partner, child, family member) is often involved in the rehabilitation needs assessment. Clearly, bias may be introduced by administration on behalf of the patient (proxy-report). Previous studies in low vision rehabilitation research revealed differences in “expected-item scores” on paper-and-pencil questionnaires, meaning that patients who self-administered the questionnaire responded in lower response-categories to certain items conditional on their disability level than patients who were assisted by someone.[46;47] For these patients a significant other is usually involved with the

intake. This example emphasizes that the D-AI should also be validated for assessment by proxy.

Target populations

In addition, the current content of the D-AI was developed specifically for visually impaired adults. Although the majority of persons entering the MRCs is indeed from this population, the concept of the D-AI also applies to other populations. MRCs have indicated that they will cooperate in the development of a D-AI for children (financially supported by Royal Dutch Visio). It is expected that developing a D-AI version for children will not be restricted to identifying a child-specific content. This will also include finding more appropriate ways to assess the problems and needs of the child and its social network. This process requires the utmost care, accuracy and extensive research.

In addition, the D-AI may be adapted for use in adults with an intellectual disability. It has become apparent that people with intellectual disability are at increased risk for visual impairment[48-52] and that, apart from having an intellectual disability, visual impairment further decreases daily living skills, communication, language and recognition.[53] Basic screening for visual impairment and more extended visual function research by the optometrist is in progress.[54;55] However, many needs may exceed those that can be supported by advice from the optometrist (such as spectacles, low vision aids or lighting advice). Moreover, persons with intellectual disability complain less about their visual loss and those without intellectual disability show less acting-out behavior.[53] From this viewpoint, it is crucial not only to screen persons with intellectual disability for visual impairment, but also to systematically assess multidisciplinary rehabilitation needs. Rehabilitation professionals, caregivers, significant others and patients themselves all have to be involved in further development of the D-AI, in order to make it applicable to this population.

Moreover, several countries already expressed their interest in using the D-AI. Although it is expected that most of the content of the D-AI will be similar in other countries, some cross-cultural differences are likely.[2] Is possible that the D-AI should not only be translated, but also adapted to the cultural-specific situation in a more profound way. Finally, to keep the D-AI up-to-date, ongoing changes in behavior and everyday technology (e.g., the need to use iPads and smart phones) warrant continuous adaptation of the content of the D-AI.

Recommendations for further validation of the D-AI

The work presented in this thesis has contributed to the development of a first draft of the D-AI. Subsequently, a larger validation study resulted in a shorter

version. As the analyses performed in this thesis were based on the previous version of the D-AI, further research on this new version is necessary. The construct(s) of tasks underlying goals should be further established by confirmatory factor analyses. Moreover, test-retest reliability should be tested for the new (formulated) goals, as well as tasks. Finally, the feasibility and interpretability of the D-AI in clinical practice should be monitored.

In addition to the analyses performed, other investigations are needed. As MRCs will be using the D-AI as part of their standard intake procedure, it will be possible to build much larger databases for the specific target population. This will enable us to apply principles from IRT models as they provide a useful method of scoring, taking into account the ordinal ratings of the items.[56-63] Since, unidimensionality and local independence are important assumptions made in these models, this is a logical consecutive step in the validation process of the D-AI which enables to accurately predict the performance of a person, i.e., the person's parameter or disability.[64;65] In addition, differential item functioning analysis is another necessary step in an IRT calibration process. This new version of the D-AI could be further strengthened by these modern psychometric techniques.

General conclusions

The aim of this thesis was to develop a valid, reliable and feasible tool to investigate and evaluate the rehabilitation needs of visually impaired adults in the Netherlands. By using input from patients and professionals, a good content and face validity was ensured. Moreover, structural validity, construct validity and internal consistency of tasks underlying the goals was sufficient for almost all of the goals that were tested. However, a larger sample is needed to further confirm the construct validity for these and other goals. Although firm conclusions concerning the responsiveness are premature, it seems that the D-AI is more responsive to measure change over time compared to the frequently used quality of life measures. Test-retest reliability analyses revealed moderate to almost perfect reliability on goal importance and difficulty for most goals. The content and/or formulation of the other goals was changed. Patients and intakers reported the instrument to be feasible. Moreover, the interpretation of the results is intuitive and can be used as input to create a rehabilitation plan. Finally, the D-AI can be used to provide better insight into the outcomes of rehabilitation. MRCs in the Netherlands now use the D-AI to set individual rehabilitation goals and to acquire a baseline measurement so that the effect of rehabilitation for individual goals can be determined with the same instrument. Future research is needed to further elucidate the psychometric properties of the new D-AI.

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