Development of the Dutch ICF Activity Inventory: Investigating and evaluating rehabilitation needs of visually impaired adults

Bruijning, J.E.

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Chapter 2

A Dutch ICF version of the Activity Inventory: Results from focus groups with visually impaired persons and experts

Bruijning JE, van Nispen RMA, Verstraten PF, van Rens GHMB.
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Abstract

Purpose: To develop a valid and reliable instrument to systematically investigate visual rehabilitation needs of visually impaired older adults, which is compatible with the “International Classification of Functioning, Disability and Health” (ICF) structure: a new Dutch ICF version of the Activity Inventory (D-AI).

Methods: The original AI was translated, adjusted and expanded. After studying literature and investigating patient records, focus group discussions were conducted until the input was just confirmatory. Six (n=41) and seven (n=50) discussions with patients and professionals respectively contributed to the first draft of the D-AI, which was further improved by professionals.

Results: The D-AI now consists of 10 domains, 68 goals and 813 tasks. Goals are organized into the “Activities and Participation” domains of the ICF. The original routing was maintained; only tasks organized under important (0 [not important] to 3 [very important]) and difficult (0 [not difficult] to 4 [impossible]) goals were assessed.

Conclusion: Rehabilitation needs can be organized in the “Activities and Participation” domains of the ICF. The D-AI offers a way of systematically assessing and measuring functional limitations and disabilities, and provides detailed information about activities that are needed to perform a certain goal. Focus group discussions with Dutch patients and experts revealed additional items that will probably be relevant for other populations. Involving patients in the first step of the developing process is important to provide face and content validity. The D-AI can prioritize rehabilitation goals by multiplying importance and difficulty scores, which is helpful in formulating a rehabilitation plan.

Introduction

Large population-based studies show that prevalence rates for visual impairment and blindness are 0.6-2.1% and 0.1-0.9% respectively.[1] As a result of demographic ageing, the number of (irreversible) visual impairments is expected to rise over the next decades. In a prognostic study by Limburg et al.[2] the prevalence of low vision and blindness in the Netherlands according to criteria from the World Health Organization (WHO) is expected to increase between 2005 and 2020 from 1.01% to 1.19% for visual impairment and from 0.40% to 0.43% for blindness. This will lead to increasing pressure on visual rehabilitation services.[3] This requires efficiently organized visual rehabilitation services in the near future.

Considering increasing health care costs and lack of manpower, it is important that visually impaired people be stimulated in maintaining their independence and that they should participate in society as much as possible.[3] The purpose of visual rehabilitation is to increase independence and participation in society,[4] either by prescribing vision-enhancing devices, or by applying multidisciplinary care such as training activities of daily living, individual or group counseling and advice on environmental modifications.[5]

In the Netherlands, three regional multidisciplinary low vision rehabilitation centers (MRCs) exist (Bartiméus, Sensis, Visio), with each several sites. The exact content of rehabilitation programs differs across these organizations, but the approach they use is basically the same. In general, these organizations have different intake procedures, for example, asking patients about their needs by telephone or relying on information obtained from the ophthalmologist. This unstructured way of investigating rehabilitation needs of visually impaired people increases the risk that the rehabilitation services are driven by supply and not by the demand of the client. Also, there is a risk that only the most prominent disability emerges during the intake procedure instead of a whole spectrum of problems. This can make the rehabilitation trajectory longer and harder than needed. Moreover, as rehabilitation needs are not investigated systematically, evaluation of rehabilitation outcome is problematic. Therefore, the MRCs stated they wanted to change their intake procedure into a more systematic approach. This implies that there is a need for an instrument that systematically investigates rehabilitation needs.

In 2001, the World Health Organization (WHO) published the *International Classification of Functioning, Disability, and Health* (ICF).[6] The use of the ICF in rehabilitation medicine is rising and the number of papers published using the ICF seems to increase exponentially.[7] Also, several insurance systems

in the Netherlands are exploring the possibilities to adapt their covering system by using the ICF. The urge for a more universal communication between health care systems, enforced MRCs' wishes in the Netherlands to describe the functioning of an individual by using the ICF structure and terminology. The ICF provides an important international taxonomy for classifying and measuring functions, disabilities, and health with standard concepts and terminology. Disorders of bodily structures lead to impairments in bodily function (i.e., disorders in the visual system result in impairments in "seeing functions"). Impairments in the visual system will usually (but not necessarily) result in disabilities in activities and participation. In the ICF structure "Activities and Participation" are divided into nine domains:[6] learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; and community, social, and civic life. The ICF classification provides an interesting structure for investigating rehabilitation needs. However, activities that represent the most detailed level of the "Activities and Participation" domains of the ICF are described only in general terms, for instance, "cleaning living area" (d6402), or "washing and drying clothes and garments" (d6400). Moreover, the ICF is not specifically based on experiences of visually impaired people. A general activity, such as using public transportation, involves many specific cognitive and visual motor activities. Specific activities that are problematic for visually impaired people are not included in the ICF. In order to assess the exact problems of visually impaired persons, a more thorough and specific assessment is needed. `Recognizing the right bus´, for example, is a typical problem for visually impaired people, but this item is not included in so much detail in the "Activities and Participation" domains of the ICF structure,[8] even though it is important to know why someone is not able to "use public motorized transportation" (d4702).

To be able to develop an assessment tool for visual rehabilitation needs, we need to assess activities more specifically. Massof et al.[8-11] published a promising model in which activities are hierarchically structured. Specific activities that are typically difficult for visually impaired people are described as "tasks". Tasks that are being performed in a coordinated manner for a common purpose represent a "goal". These goals are classified by their "objectives". Massof et al.[9,10] formulated five objectives: daily living, social participation, recreation, education and vocation. The first three objectives were already built up in the original Activity Inventory (AI).[8,9,11] According to Massof et al.,[9,10] a person cannot perform specific tasks if he/she experiences functional limitations. In turn, a person experiences disabilities if relevant goals cannot be achieved. Thus, people are only disabled if the activities that are unusually difficult or

impossible to do, are those that the person really wants or needs to do. Therefore, the AI rates the importance of each goal on a scale of 0 (not important) to 3 (very important). If the goal is important, the difficulty of this goal, caused by the visual impairment, will be rated on a scale of 0 (not difficult) to 4 (impossible). Only goals that are at least “a little important” and “a little difficult” will be fully assessed at task level.[9] As the purpose of rehabilitation is to decrease visual disability, the difficulty of important goals must be reduced. Thus, the effect of rehabilitation should be reflected at the goal level.[8,9] Moreover, the responses can be used to build a rehabilitation plan by multiplying the goal importance rating by the goal difficulty rating to calculate a rehabilitation demand score for each goal (priority score), and, consequently, to prioritize the goals by their scores in a priority list. Hence, assessing the AI is a promising way to investigate and evaluate rehabilitation needs.

Some available questionnaires measure vision-related quality of life as a global outcome of rehabilitation.[12-15] However, to our knowledge, besides the AI, there is no validated instrument available to systematically assess rehabilitation needs of visually impaired older adults. The ICF is a useful tool to describe the functioning of an individual, but it is not an assessment tool itself. In recent years, some condition-specific core-sets have been developed (e.g. core sets for patients with chronic conditions or patients with a depression[16,17]). These are presented as a possible approach to implement the ICF in rehabilitation practice for assessing rehabilitation needs based on the ICF. However, no low vision specific core-set is currently available.

The aim of this study is to create a new (Dutch) version of the AI in which goals will be classified by the “Activity and Participation” domains of the ICF; and second, we want to explore if the AI represents all important topics for visually impaired persons, even outside the United States. To enable scientists and other professionals to have insight in the development and validity of the Dutch ICF AI (D-AI), this paper describes the first step in the process, using a literature study, patient records and focus group discussions.

Subjects and methods

Translation AI

An updated version of the original AI, obtained from Massof (unpublished data), was translated into Dutch. Forward and backward translations were performed by translators, who were native English speakers. The translations were compared and a final form was devised.

Study population

In order to expand and adjust the existing AI, focus group discussions were organized. Six focus groups with 41 visually impaired people were conducted as well as seven focus groups with 50 rehabilitation professionals (experts), to further explore the field of patients´ visual rehabilitation from different stakeholders' perspectives. The study protocol was approved by the Medical Ethics Committee of the VU University Medical Center Amsterdam and was consistent with the principles of the Declaration of Helsinki. All patients provided a written or oral informed consent.

Efforts were made to include patients with different characteristics. Therefore, some younger working visually impaired persons were included as well. Adult participants had to; experience problems in daily activities caused by their visual impairment; be able to speak Dutch, and; have sufficient cognitive function to take part in a discussion. Patient focus groups were composed with the help of contact persons of MRCs and patient organizations. An advertisement on the Internet did not result in any participants. Because many visually impaired people have transportation problems, discussions were held at several locations in the Netherlands (e.g. MRCs or patient organizations).

Focus groups with professionals working at the MRCs were arranged. Of all three MRCs, team managers were asked to recruit experts in the field of low vision rehabilitation by informing as many colleagues as possible. The experts received an e-mail about the objectives and the intention of the discussion. In order to minimize time pressure at work, participants were clustered per location.

Focus group discussions

Following Vaughn et al.[18] a structured protocol was used during the focus groups. A short version of the protocol for patient focus groups is presented in Table 1. Most discussions were moderated by JEB and RMAvN. Participants were asked about their experiences concerning rehabilitation (needs) of visually impaired people. The number of focus groups was not defined beforehand. Additional focus group discussions were conducted until the input was just confirmatory.

Additional data collection

To gain additional information, the "Information shop" of Sensis was visited and three home visits of an occupational therapist were attended to spot yet undetected rehabilitation needs. Moreover, data of patient records of 192 visually impaired people were screened for rehabilitation needs as stated by the referrer (mostly the ophthalmologist) and the low vision specialist[19]. Ninety-five patient

records were from an optometric service and 97 records were from an MRC. Finally, items of other questionnaires in relation to low vision were studied and added if the item was not covered yet (e.g. references[20-30]). In this way, we collected as much rehabilitation needs as possible in order to construct an extensive item pool for the questionnaire.

Analyses

Organizing data

During each focus group, all issues that were mentioned were written down by the discussion moderator. Notes were typed and audio tapes were used if the notes were incomplete.

Activities that served a common purpose were put together. This process was data driven and activities that were taken together were named after the goal they served. For example activities like “judge browning or doneness of food,” “adding salt, pepper and spices,” and “varied cooking” were put together and labeled by the goal “meal preparation.” Sometimes highly comparable issues were taken together, such as, “recognizing different kinds of meat in the refrigerator” and “recognizing different kinds of meat in the freezer.” Finally, some items concerning specific hobbies were omitted from the original AI.[8,9] All goals obtained from focus groups, literature, patient records and an updated version of the original AI (Massof, unpublished data) were categorized by the nine “Activities and Participation” domains of the ICF. For feasibility reasons some deviations from the ICF structure of “Activities and Participation” were made.

After all tasks were categorized by goals and all goals were classified by domains, all items were transformed into questions. A first draft was created by JEB and then reviewed by RMAvN. If both authors disagreed about a formulation, a discussion took place until consensus was reached. Subsequently, the new D-AI was sent to 25 experts working at MRCs. Experts were asked to review a specific domain of their expertise or the entire D-AI, concerning the content, the classification and the formulation. Twelve experts gave their written feedback, two of them did not participate in the focus groups before. Each domain was reviewed by at least three experts. Some experts made some small adjustments in the exact wordings of a question, and others added or deleted some questions. Finally, PFJV evaluated the classification by the ICF.

Table 1. D-AI: sample text from focus group protocol.

1. Introduction

- Welcome participants
- Moderator(s)/researcher(s) introduce themselves
- Explanation of process
    - maximum of 2 hours
    - read aloud the information letter to be sure that all participants share the same content
    - discussion will be audio taped and tapes will be erased after they have been analysed
- Explanation of the goals of the discussion
- Participants provide a written or oral informed consent (if not returned before)

2. Personal information

Ask participants to introduce themselves. Where do you live? Do you live alone or together with others? What is your age? What do you do in daily life? Could you tell us something about your eye condition? Since when do you suffer from your eye condition? How would you describe your current vision in your own words?

3. Rehabilitation needs in relation to visual impairment

Open-ended questions, which can be used to keep the discussion going. Examples are:
What aspects of daily life are most affected by your vision? What do you miss most since you have become visually impaired? What has been changed in your life? What did you expect from rehabilitation? What was useful during rehabilitation and what did you miss? What were you scared of when you became visually impaired? How do you cope with your vision loss?

3A. If discussion is outgoing

Ask open-ended questions about the influence of vision on subjects such as social participation, recreational activities and employment.
If necessary more specific areas can be introduced: For example: social interaction with family, friends or colleagues, mobility, sports, vacation or finding help and information.

3B. If there is some time left

Some other topics can be addressed. What things does someone else do for you, because of the fact that you cannot do these things anymore? Could you give an example of things you can do now, but which took a long time before you could? What would you like to learn in the future?

3C. If answers are unclear or not specific

The following questions can be asked: Could you clarify that? Can you be more specific? Could you give an example? Why? What do you mean by that?

4. Closing

- Answer questions of participants
- Thank participants

The D-AI and its routing were programmed using Blaise Enterprise 4.7 (Heerlen, The Netherlands). In this way, it can easily be assessed using a Computer Assisted Telephone Interview.

Results

Focus groups and participants

The input in the sixth and seventh focus groups for patients and experts respectively, was just confirmatory. Overall, 41 patients and 50 experts took part in the discussions.

The mean number of patients per group was 6.8 (range: 4-11). Patient characteristics and eye conditions were very diverse and some patients suffered from more than one disease. Characteristics of the participants are presented in Table 2. Many participants reported that the visual acuity loss was not the only reason for their visual disability; a number of people suffered from visual field loss, neurological problems (e.g. diplopia) or had problems with low or high light levels. The mean number of participants in the expert focus groups was 7.1 (range: 4-13). Experts came from eight different locations of all three MRCs. Expert characteristics are presented in Table 3. Patients and experts discussed many similar topics. However, as can be seen in Table 4, they complemented each other in some topics.

Structure and content of the D-AI

The first draft of the D-AI consists of 68 goals and 813 tasks (Table 4). The structure of tasks and goals, nested under the “Activities and Participation” domains of the ICF provided a helpful approach to systematically asses goals that were included in the first draft of the D-AI.

The original AI was modified in some important points. Some tasks in the original AI seemed to be perceived as goals by the participants. For example, the mobility item “getting at the location” was only present as a task underneath several goals. In the D-AI, mobility issues are brought together in one “mobility” domain (d4) and then split into several goals such as “riding a bike” or “using public transportation”. These goals are now built up by very detailed tasks, e.g. “buying a ticket at the ticket machine” and “recognizing the right stop”. Yet, the item “getting at the location” is still present as an activity of various goals. Another example of a modification is that in the original AI “watching TV” is present as a task underneath the goals “leisure entertainment” and “follow the news”. This means that the item “watching TV” will not be assessed if these

Table 2. Characteristics participants of patient focus groups

Characteristics	Specification	Number of participants n = 41 (%)
Age	Mean (±SD)	65 (±16.5)*
Sex	Male	22 (54)
Self-reported main problem of visual loss in the better eye	Visual acuity in Snellen:	
	≥ 0.3	6 (14.6)
	< 0.3 and ≥ 0.1	4 (9.7)
	< 0.1 and ≥ 0.05	4 (9.7)
	< 0.05 and ≥ 0.02	6 (14.6)
	< 0.02 and ≥ light perception	11 (26.8)
	No light perception	1 (2.4)
	Visual field loss	3 (0.07)
	Diplopia	1 (2.4)
	Unknown	5 (14.6)
Self-reported eye condition	Age-related macular degeneration	12 (29.3)
	Diabetic retinopathy	3 (7.3)
	Unspecified retinal damage	13 (31.7)
	Glaucoma	7 (17.1)
	Unspecified optic nerve damage	6 (14.6)
	Cataract	3 (7.3)
	Unspecified cornea diseases	3 (7.3)
	Unspecified trauma	1 (2.4)
	Unknown	4 (9.8)
	More than one eye condition	9 (22.0)
Progression and/or onset of Low Vision	Slowly progressive	21 (51.2)
	Sudden deterioration	8 (19.5)
	Slowly progressive with sudden deterioration	6 (14.6)
	Blind from birth	1 (2.4)
	Unknown	5 (12.2)
Rehabilitation state	Rehabilitating at MRC[#]	10 (24.4)
	Rehabilitation finished	20 (48.8)
	Living in a home for visually impaired persons	11 (26.8)
Living area	Urban	14 (34.1)
	Rural	22 (53.7)
	Unknown	5 (12,2)
Living state	Alone/widow(er)	15 (36.6)
	Partner	12 (29.3)
	Unknown	14 (34.1)
Work	Still working (paid or volunteering)	15 (36.6)
	Not working anymore because of low vision	3 (7.3)
	Not working because of age	22 (53.7)
	Unknown	1 (2.4)
Organisation by whom the patients were recruited		
MRCs[#]: Visio	(Ex-)rehabilitants and participants from a moulding class at 'Visio'	9 (22)
MRCs[#]: Visio & Sensis	Members of the Client Board	4 (9.8)
MRCs[#]: Sensis	ICT training class	6 (14.6)
MRCs[#]: Sensis	Recreational activity class	4 (9.8)
Patient organisations	Members and visually impaired employees	7 (17.1)
Nursing home for visually impaired persons	Residents	11 (26.8)

* Mean (± SD) instead of 'Number of participants (%)'
[#] MRC: Multidisciplinary Rehabilitation Center

Table 3. Characteristics participants of expert focus groups

Characteristics	**Specification**	**Number of participants n = 50 (%)**
Profession	Occupational therapist (with different expertise)	18 (36.0%)
	Social worker	7 (14.0%)
	Low vision specialist	5 (10.0%)
	Reintegration/employment expert	4 (8.0%)
	Recreational or creative therapist	3 (6.0%)
	ICT expert	3 (6.9%)
	Intake expert or rehabilitation coordinator	5 (10.0%)
	Employee 'information and advice´	2 (4.0%)
	Other	
	Psychologist	1 (2.0%)
	Psycho diagnostic worker	1 (2.0%)
	Braille trainer	1 (2.0%)
	Mobility expert	1 (2.0%)
	Project manager 'development and Implementation'	1 (2.0%)
	Employee 'Client Services'	1 (2.0%)
	Unknown	1 (2.0%)
	More than one function	4 (8.0%)
Name of MRC* represented by participant	Bartiméus (with 2 sites)	14 (28.0%)
	Visio (with 2 sites)	15 (30.0%)
	Sensis (with 4 sites)	22 (44.0%)
	Working at more than one site	2 (4.0%)

* MRC: Multidisciplinary Rehabilitation Center.

Table 4. Global content of D-AI: specific Goals and number of Tasks of D-AI for pilot

Chapter	Domain (ICF 'Activities and Participation')	Number of goals	Total number of tasks	Number of tasks	Goal
1	**Learning and applying knowledge**	3	29	13	Reading
				6	Writing
				10	Watching TV
2	**General tasks and demands**	2	16	10	Personal administration
				6	Follow a schedule
3	**Communication**	3	38	23	Using computer at home
				8	Personal correspondence
				7	Using telephone
4	**Mobility**	8	140	9	Mobility at home
				11	Mobility indoors somewhere else
				22	Walking outdoors
				24	Driving a vehicle for disabled people
				17	Riding a bike
				17	Riding a motorised bike/moped/scooter
				24	Driving a car
				16	Using public transportation
5	**Self-care**	5	76	13	Dressing
				20	Personal hygiene
				8	Using a public toilet
				24	Personal heath care
				11	Eating and drinking
6	**Domestic life**	12	166	16	Household tasks
				8	Doing laundry
				11	Doing chores at home
				6	Mending clothes
				9	Withdraw or dealing with money
				27	Daily shopping
				28	Daily meal preparation
				9	Guide dog care
				12	Pet care
				4	Shopping
				21	Health care for an adult
				15	Child care
7	**Interpersonal interactions and relationships**	6	57	16	Recognition and communication
				8	Interaction with partner
				8	Interaction with family
				4	Interaction with relatives and friends
				15	Interaction with colleagues
				6	Interaction with strangers
8	**Major life areas**	9	97	13	Manage finance
				4	Manage difficult financial situations
				8	Regulatory and information
				12	Education
				5	Apply for a job
				9	Accessibility at work
				12	Working activities
				22	Using computer at work
				12	Attend meetings

	Topics covered by patients^	Topics covered by experts^	Topics covered by patient files^	Topics covered by updated$ AI^
	x	x	x	x
	x	x	x	x
	x	x	x	x
	x	x	x	x
	x	x	x	x
	x	x	x	x
	x		x	x
	x	x	x	x
	x		x	
	x	x		
	x	x	x	
		x		
	x			
		x		
	x	x	x	x
	x	x		x
	x	x		x
		x		x
	x			x
	x	x	x	x
	x	x		x
	x	x	x	x
	x	x	x	x
	x			
	x	x		x
	x	x	x	
	x	x	x	x
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		x		
				x
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	x	x		x
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	x	x		x
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	x	x		
	x	x		x
	x			
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	x	x		
	x	x		
		x		
	x	x		
	x	x		
		x		x

Table 4 (continued)

Chapter	Domain (ICF 'Activities and Participation')	Number of goals	Total number of tasks	Number of tasks	Goal
9	**Community, social, and civic life**	12 5	137 22	16 11 17 24 19 3 14 12 4 4 7 6 5 2 1 6 8	Follow the news Intellectual activities Having visitors Social events Dining out Social activities and trips Going on holiday Gardening Making music Perform in public Watching TV or movies (recreational) Using specific ICT tools Attend cultural event# Playing games# Creative activities# Hobbies and crafts# Play sports#
10	**Mental (emotional) health Aspects***	3	35	9 11 15	Feeling fit Handle feelings Acceptance
	TOTAL	68	813	813	

* nd-mh: not definable-mental health as stated by Cieza et al. (2005); # Additionally, these goals include open-ended goal-questions and open-ended task-questions about possible hobbies; ^ 'x' means that this goal or at least one task (which was not already present in another goal) underneath this goal was covered; $ Massof has made an ´updated´ version of the original AI. This updated version (which has not been published) has been used to further expand the AI.

	Topics covered by patients[^]	Topics covered by experts[^]	Topics covered by patient files[^]	Topics covered by updated[$] AI[^]
		x		x
	x			
	x	x	x	x
	x	x		x
	x			x
	x			x
	x			
	x			x
	x	x		x
	x			x
	x		x	
	x	x		
	x	x		x
	x	x	x	x
	x	x	x	
	x	x	x	x
	x	x	x	x
	x	x		
	x	x	x	
	x	x	x	

goals are perceived as not relevant, even though many participants indicated that “watching TV” was problematic. Therefore, this was now inserted as a goal with different activities like “reading subtitles” and “recognizing faces on TV”. A similar approach was applied to “reading” and “writing” related goals, as well as to goals concerning “interpersonal interactions and relationships”.

In addition, some goals concerning “employment” and “education” were added. However, some hobby related goals like “hunt and shoot” and “leatherwork” from original AI were left out of the D-AI, because the patient files and focus groups made it clear that these hobbies are not common. The original routing structure from the AI was copied (Figure 1). However, in the D-AI five goals (“attend cultural events”; “playing games”; “creative activities”; “hobbies and crafts”; and “play sports”) are built up by sub-goals (n=47), including sub-tasks (n=97). These sub-goals are specific and personal hobbies such as “attend a movie in a cinema” and an open ended question in which the visually impaired person can bring up his/her own personal hobbies (e.g. “leatherwork”).Sub-goals will be assessed only if the general goal is important and difficult for the patient. Finally, a tenth domain (which is not covered by the “Activities and Participation” domains of the ICF) “coping with mental (emotional) health aspects” was inserted in the D-AI.

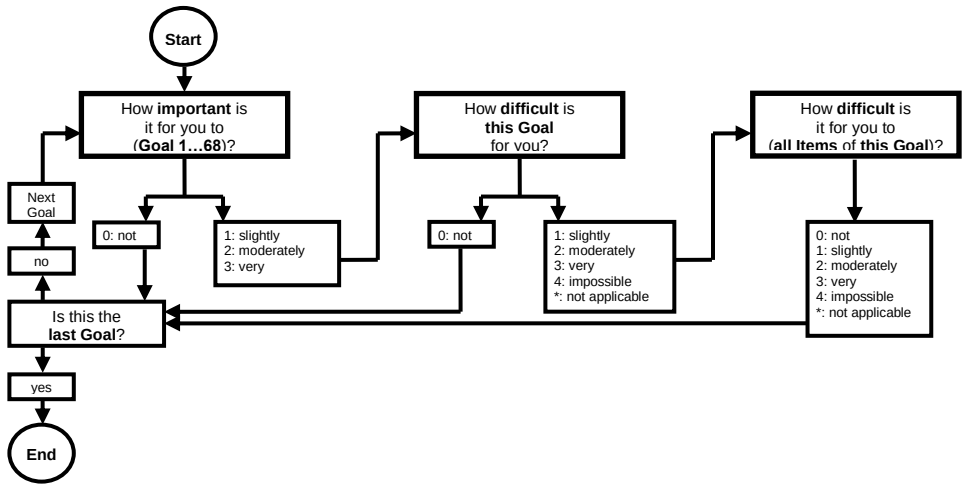

Figure 1. Routing of D-AI

Table 5. An example (Goal 5: "Follow a schedule") of the exact wordings of the questions

Kind of question	Exact wordings of the question	Answer categories
Goal Importance	How **important** is it for you to be **attentive to your schedule** without anyone else's assistance, for example to be **in time for an appointment**?	0 Not important 1 Slightly important 2 Moderately important 3 Very important
Goal difficulty	How **difficult** is it for you to be **attentive to your schedule** without anyone else's assistance, for example to be **in time for an appointment**?	0 Not difficult 1 Slightly difficult 2 Moderately difficult 3 Very difficult 4 Impossible to do without someone else's help
Task difficulties	How **difficult** is it for you to…	
Task 5.1 difficulty	**read appointments** in your agenda or calendar?	0 Not difficult 1 Slightly difficult 2 Moderately difficult 3 Very difficult 4 Impossible to do without someone else's help NA Not applicable
Task 5.2 difficulty	**read hand written notes** in your agenda or calendar?	
Task 5.3 difficulty	**make notes** of appointments you make in your agenda or calendar?	
Task 5.4 difficulty	**read a clock**?	
Task 5.5 difficulty	**use your watch**?	
Task 5.6 difficulty	**set an alarm**?	

Mean number of tasks of the D-AI that belonged to a goal (disregarding sub-goals) is 12.6 (±6.4; range 3-28 tasks). To give some impression of the content of the questionnaire the tasks of the goal "follow a schedule" are presented in Table 5.

Discussion

In this study, we described the developmental process of a first draft of the D-AI. We used the "Activity and Participation" domains of the ICF to classify goals, which may support the use of the ICF model in daily rehabilitation practice. After studying the literature, exploring patient records, and conducting focus groups, the AI was extended and adapted. In the new D-AI, the number of goals and tasks increased 65.9% and 142.2% respectively.

The value and application of the ICF in rehabilitation medicine has been widely discussed.[31] The success of the ICF to serve as a globally agreed terminology will largely depend on its acceptance with rehabilitation medicine practitioners.[32] MRCs in the Netherlands have expressed interest in using the

ICF to better understand and communicate about the needs of their patients, starting in the intake phase by an assessment. Of all goals, which are perceived as important to the patient, the patient will rate the difficulty in his own environment. In the ICF expressed as “performance” instead of “capacity”.[6] The priority score reflects the relevance of a goal and therefore plays an essential part in the determination of intervention targets, which is an important part of the rehabilitation process. Existing questionnaires, as well as the ICF-core-sets do not assess the relevance of a goal.

In developing the D-AI, we included goals and tasks that are generally problematic for visually impaired people. In contrast to the most specified level of the “Activities and Participation” domains of the ICF, it can be seen that activities -and sometimes even goals- in the D-AI are formulated in much more detail. For instance, goals such as “driving a car” or “riding a vehicle for disabled people” are not explicitly listed in the “Activities and Participation” domains of the ICF, but fall into the category “driving motorized vehicles´ (d4751). Tasks and goals in the D-AI are typically difficult to perform for visually impaired people and they refer directly or indirectly to visual functions. With the assessment of the D-AI, difficulty scores of activities can be related to specific visual functions, as was presented by Massof et al.[8]

As stated by Stucki et al.[32] the key to a successful rehabilitation management is the understanding of the relationship between selected target problems, impaired body functions and structures, psychosocial factors, and environmental factors. Therefore, these other factors still need to be investigated, next to the assessment of the D-AI. In the near future, the (vision-related) tasks in the D-AI need to be linked to (visual) functions following the ICF linking rules by Cieza et al..[33] Subsequently, we have to link the activities of relevant goals to specific low vision aids, rehabilitation programs and/or interventions. ICF Assignment Maps could be helpful to choose proper interventions for specific problems.[34] This may provide insight into which type of rehabilitation program is appropriate for an individual.

An important alteration was to add a tenth domain to the D-AI, which is not included in the “Activities and Participation” of the ICF; “coping with mental (emotional) health aspects’. In the focus groups, experts as well as patients asserted that these are important topics to investigate as part of the intake and that the rehabilitation outcomes of “coping with mental (emotional) health aspects” should also be evaluated as part of the Activity and Participation domains. However, it was preferred to mention these in the last part of the questionnaire, because of the emotional impact these questions may have.

As can be seen in the results section, some re-arrangements were made. This may be (partly) attributed to the differences in population characteristics between people in the US and the Netherlands. To give an example; in the US bikes are used merely recreationally or for sports. In the Netherlands, riding a bike is a very common way of transportation. Therefore, the item "go biking," nested only under the goal "outdoor activities" was not appropriate for the Dutch population. Some other changes are less population specific, such as "watching TV". By rearranging specific tasks and goals in the original AI, we believe that rehabilitation needs and rehabilitation outcome can be investigated more specifically.

An important component of our study design was the use of focus groups, which supplies an efficient way of gaining an overview over various opinions at a detailed level.[35,36] By using focus groups, items in the D-AI refer to relevant aspects of the construct being measured in this population, which makes the items relevant for the purpose of the application: building a personal rehabilitation plan from the patient's perspective. Using qualitative techniques in the target population until the focus group information was just confirmatory, provides face and content validity.[37]

However, the study design also has a number of limitations. In using focus groups care should be taken not to influence participants by confronting them with preconceived ideas. In order to address this issue, the discussion guide was formulated in neutral terms (Table 1). Another point of concern was the study population. It is remarkable that more men took part in the focus groups, since women have a majority in this age group.[2] However, in developing a non disease specific questionnaire which is suitable for all MRC patients, we considered it less important to focus on socio-demographic characteristics. Patients were invited if they belonged to the specific user group ([ex] patients of MRCs, regardless of minimal currently corrected visual acuity, the maximal visual field, or eye conditions), which is essential in order to optimize the validity of the instrument.[38] Also, despite the fact that the objective of our study was to develop an instrument that investigates rehabilitation needs of (older) adults, we had to involve some younger participants in order to include more diverse patient characteristics. Additionally, for feasibility reasons, we could only include Dutch speakers with a sufficient cognitive ability. It is important to consider that the content of the D-AI will not be directly applicable to, for example, children, mentally disabled people or patients in developing countries. Further research is necessary to determine to what extent the AI is applicable to these groups. However, because of the routing of the AI, additional items can only be of added value, as goals which are irrelevant for an individual will not be fully assessed.

In contrast to the study of Mangione et al.,[25] but similar to Slavin et al.,[39] we did not quantify how many participants mentioned a specific item. Following Creswell[35] quantitative validity plays a minor role in qualitative inquiry. First, when conducting focus groups, it does not necessarily mean that if an item is only mentioned once or twice it is not important or difficult for many others. Second, in this phase of the study we tried to be as complete as possible. As we wanted to investigate personal rehabilitation needs, a short screening list may not be satisfying. On the other hand, a long questionnaire is not feasible in daily practice. However, upcoming quantitative analysis will address this point. At this moment, the AI consists of many more items and therefore will probably take more time to assess. However, due to the routing structure, only relevant goals (important and difficult) will be fully assessed.

In conclusion, the findings in this study have identified the content area for a first draft of the new AI. Goals were categorized by the "Activity and Participation" domains of the ICF. Promising of this questionnaire is that it is a very detailed way of investigating rehabilitation needs of visually impaired (older) adults, using the ICF. Moreover, priority scores will result in a priority list, which helps to set rehabilitation goals. In order to improve the exact classification of goals and tasks, the exact content, and wordings of the AI, a pilot study will be performed. Among 20 visually impaired older adults with rehabilitation needs, who enter the MRC "Sensis" in the Netherlands, feasibility of the AI will be tested. Subsequently, in larger validation study, reliability and validity of the new AI will be tested, using item response models.[40,41] In this way, we believe that the basis for an international assessment tool to investigate visual related rehabilitation needs will be available.

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