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Research Article

Overview of ICF Categories Addressed within Outcome Measures Applied in Prognostic and Intervention Studies for Non-Specific Complaints of Arm, Neck and Shoulder

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Abstract

Background: Non-traumatic complaints of arm, neck and shoulder (CANS) are an important health issue. Although CANS may vary in clinical expression and underlying causes, data on sick leave and healthcare use show that, especially chronic CANS, has a major impact on functioning and health. There is a need for more insight into the physical, emotional and social challenges of patients with CANS.

Aim: To present an overview of relevant outcomes regarding functions, activities and participation, in patients with complaints of arm, neck and shoulder (CANS) and their association with the International Classification of Functioning, Disability and Health (ICF).

Design Linkage study, linking items of outcome measures to ICF-categories.

Methods: A literature search was made for articles on prognostic and intervention studies, as part of the development of the Dutch multidisciplinary evidence-based guideline for non-specific CANS. Outcome measures of each article were extracted and categorized into those on physical health and mental health. All items of these measures were linked separately to the ICF following internationally developed linking rules. All ICF categories used in at least 5% of the studies are listed, following new recommendations for the development of ICF core sets. Additionally, the distribution of ICF categories across all ICF categories within the outcome measures is evaluated.

Results: A total of 123 original studies were included. The 'top 20' of ICF categories related to physical health and mental health are listed, together with the cumulative percentage of all the applied ICF categories. Also reported are all ICF categories used in at least 5% of the studies, as well as the frequency of the total number of applied ICF categories.

Conclusions: Aspects of function, activities and participation were identified in outcome measures used in studies on CANS and linked to the ICF, based on the literature included in the multidisciplinary guideline for non-specific CANS.

Clinical Rehabilitation Impact: The results of this study can serve as a preparatory study for the development of an ICF core set for CANS, which can be applied in rehabilitation care for patients with (chronic) CANS.

Keywords: International Classification of Functioning (ICF); Disability and Health; Neck complaints; Shoulder Complaints; Upper Extremity Complaints; Complaints of Arm, Neck and Shoulder (CANS); Outcome Measurement

Introduction

Non-traumatic complaints of arm, neck and shoulder (CANS) are an important health issue, with high point prevalence rates in general working age populations ranging from 12% in the USA to 33% in the Netherlands and 44-52% in the UK [1-5]. In the Netherlands, these complaints were often referred to as repetitive strain injury; however, this term is now considered ill-defined and leads to much confusion because it suggests an eliciting injury, whilst (often) no disorder is present that can be determined objectively [6,7]. In the Netherlands a terminology project was initiated to improve the nomenclature regarding neck and upper extremity disorders as a basis for more effective collaboration between care providers. In 2004 this resulted in a multidisciplinary consensus, appointed as the CANS model [8]. All Dutch organizations of relevant medical and allied healthcare professionals were involved in this project. CANS was defined as: '*Musculoskeletal complaints of arm, neck, and shoulder not caused by acute trauma or by any systemic disease*'. The CANS model differentiates between specific and non-specific disorders. It provides an overview of all specific disorders that can be included under this definition of CANS. If no specific condition can be diagnosed, the complaints should be classified as non-specific CANS. In general practice, the ratio between specific and non-specific complaints is estimated at about 3:2 [9].

Although CANS may vary in clinical expression and underlying causes, data on sick leave and healthcare use show that, especially chronic CANS, has a major impact on functioning and health. In the Netherlands, about 19% of people with chronic CANS reported interdependent sick leave, of which 39% with a duration ≥ 4 weeks [2]. CANS has been registered as the cause of almost 11% of all sick leave days in the Dutch workforce [10]. In the USA, upper extremity disorders are accountable for about 4.4% of sick leave claims [11]. Although in 63-70% of registered cases no time lost from work was claimed for compensation [12,13], the mean time lost was ≥ 70 days and much greater compared to the mean of other causes, and 3-5% of people who filed a sick leave claim were unable to return to work [14]. However, these data are probably an underestimation, because many workers experienced recurrent spells of sick leave due to the same complaints. In that same study, additional analyses on data from Canada indicated that 26% of workers who experience a first period of sick leave due to CANS also experience a second, and 5% a third period [14].

In the Netherlands, of the patients with chronic CANS about 58% have consulted one or more healthcare professionals, most often a general practitioner (81%), medical specialist (59%), and physiotherapist (54%). Due to the considerable uncertainty regarding the diagnosis and treatment of CANS in the Netherlands, the development of a multidisciplinary guideline was started in 2010 [15]. In November 2012 the final version of the guideline was authorized by the participating professional organizations and patient association [16]. Because of the impact of CANS on functioning and participation, during the guideline development special attention was paid to the association between CANS and the International Classification of Functioning, Disability and Health (ICF). There is a need for more insight into the physical, emotional and social challenges of patients with CANS. The ability to adapt to these challenges, whether by self-management or with the support of health care, largely defines a person's dynamic health status [17]. However, the guideline development process and the resulting guideline focused mainly on the evidence for the diagnosis of specific and (by exclusion) non-specific CANS, as well as the treatment of non-specific CANS. No in-depth study on the association between non-specific CANS and the ICF was feasible within the available time frame. Therefore, after publication of the guideline [15,16]. the present study was conducted to provide an overview of relevant outcomes regarding functions, activities and participation among patients with CANS, and their association with the ICF.

Methods

Literature search

The development of the multidisciplinary guideline on non-specific CANS followed the method of evidence-based guideline development [16,18]. An extensive literature search was performed by an experienced librarian of the Dutch Institute for Healthcare Improvement (CBO). The search was made in Medline and Embase in the period November 2009-May 2010 and covered the period from 1995 onwards. Only articles in English, German or Dutch were included. All search procedures and terms are reported in Appendix 3 of the guideline [16].

In addition to the literature review, members of the expert group for the development of this guideline were allowed to propose additional articles that they had missed in the search results.

This search strategy encompasses all studies that contributed to the evidence-based guideline on CANS, and this body of literature was also used for the present study. From the included systematic reviews, all original articles were retrieved for data extraction.

As the present study focuses on measurement of outcomes related to functions, activities or participation of patients with CANS, we selected all articles with prognostic and intervention studies. Although the search focused on studies including patients with non-specific CANS, we assume that most of the measurements utilized are applicable for all types of CANS, whether they be specific or non-specific, or a combination of both.

Outcome Measurement

Outcome denotes the effects of healthcare (interventions) on the health status of patients and populations, including behavioral changes, improvements in knowledge, and satisfaction with health care [19]. Changes in health status over time, given the availability of more or less developed health care, fall under this definition of outcome. An outcome of interest may be observed at clinical examination of the patient, or with use of imaging techniques, or as measured by a physical or laboratory test, or a patient-reported outcome. When an outcome is measured by information that comes directly from the patient (i.e., without the interpretation of the patient's responses by a (health) professional or anyone else) the term patient-reported outcome measure (PROM) can be used [20]. These measures were developed to investigate the personal views and experiences of the patient. PROM data may be collected via self-administered questionnaires, or by interviews. For measurement purposes, the answers to the questions are predefined so that the patient can select the best option from several possible answers, or can indicate the magnitude of the outcome on a numeric rating scale (NRS) or a visual analog scale (VAS). The measures may be generic (designed to be used in any population and to cover a broad overview of the construct under study), or condition-specific or disease-specific (developed specifically to measure aspects of outcome in a population with a specific medical condition) [21]. However, when a measure that is intended to be specific addresses more than one construct, the traditional division into generic and specific measures becomes less clear [20]. Examples of constructs are (in ICF terms) impairments (often reflecting symptoms), limitations in activities, participation restrictions, environmental factors, and personal factors (including quality of life) [22].

Some PROMs consist of a single item or indicator, such as self-rated health or a VAS for pain. These measures assess a single underlying construct and are called unidimensional PROMs. Other PROMs are multidimensional and comprise several scales that each address a single construct [20]. The multiple constructs create a profile of various outcomes [23]. In some of these measures an overall (single summary) score is created; however, these summary scores are often difficult to interpret because the contribution of each construct remains unclear.

Data extraction and linkage procedure

The outcome measurements in the selected studies are extracted from the method section of each article by two authors (AF, EK) independently. Measures of prognostic, etiological or confounding factors are not included. In the case that several articles publish results on the same research project, all outcome measures are extracted but the study is counted only once in the analyses.

In the selected studies, all items of (all constructs of) the outcome measures are linked separately to the ICF. When insufficient information was given with regard to all items of a PROM that was utilized in a study, an example is retrieved from the literature or requested from the authors. Each separate item of every outcome measure is translated into one or more meaningful concepts (MCs), in order to be linked to the corresponding ICF categories. A MC is the smallest distinct part of the item text that represents a specific common theme [24]. For instance, item 13 of the Disability of Arm, Shoulder and Hand Questionnaire (DASH) 'wash or blow dry your hair' contains two MCs: 'wash hair' and 'blow dry hair' [25]. These are linked to separate ICF categories (i.e., d5100 'washing body parts' and d5202 'caring for hair', respectively).

Figure 1 presents an overview of the structure of the ICF [26]. Both parts of the ICF are available for linkage of MCs and each consists of two 'Components', i.e., 'Functioning and Disability' contains 'Body Functions and Structures' and 'Activities and Participation', and 'Contextual Factors' contains 'Environmental Factors' and 'Personal Factors'. Each component (except for 'Personal Factors') has one or two categories, indicated by a letter ('b' for functions, 's' for

structures, 'd' for activities and participation and 'e' for environmental factors). Within each category this letter is followed by a maximum of five numbers, indicating four possible levels of specification (because the second level contains three numbers and there is no level with two numbers. For examples, see tables 3 and 4). The first level (with one number) is also called a chapter.

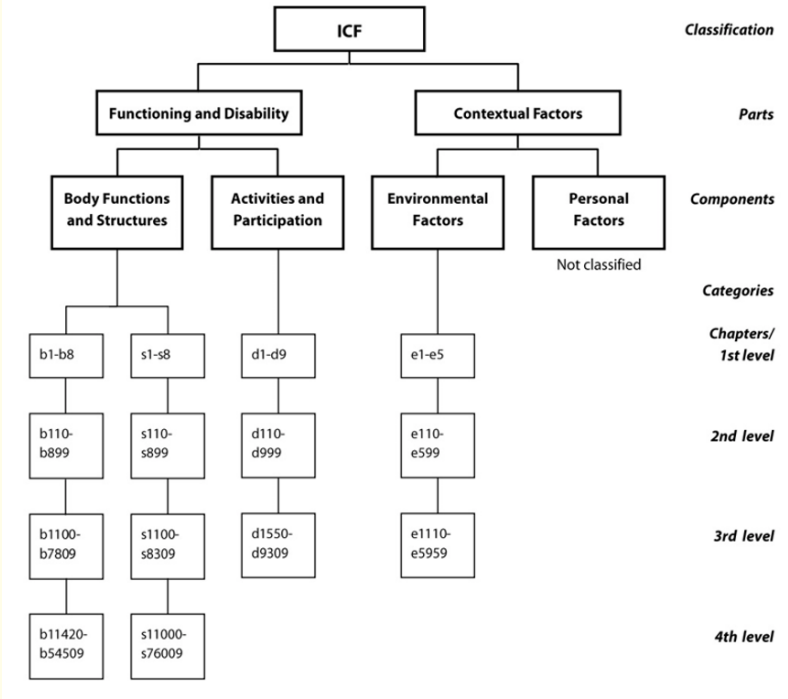

Figure 1: Structure of the International Classification of Functioning, Disability and Health (ICF) [26].

The linking procedure consists of a set of 12 linking rules [24]. All MCs that are contained within the selected outcome measures are formulated based on (part of) each item text and then linked to the most specified level of an ICF category. When a MC is not fully congruent with (a part of) an ICF category, additional information is noted. If a MC cannot be linked to any ICF category, it can be classified in four ways: 1) If the MC is not sufficiently specified to make a decision regarding which ICF category should be selected, but is clearly related to one of the components, the letter of that component is noted (b, d or e); 2) If a MC refers to a personal characteristic, the component 'personal factor' (pf) is noted: for example MCs referring to lifestyle, habits or attitudes are classified as pf; 3) If a MC cannot be linked to any ICF component, the option 'not definable' (nd) is chosen, combined with general health (nd-gh), physical health (nd-ph), mental health (nd-mh) or quality of life (nd-qol): for example, general concepts such as 'health', 'condition', 'symptoms' or 'recovery' are considered not to be definable for linking; 4) If a MC was outside the domain of ICF the option 'not covered' (nc) is selected.

Two authors (HM, EK) performed the linking procedure independently. Any disagreement was resolved through discussion, or through recourse to a third independent author with ample experience with the linking rules (YH). This third author also checked all other ICF categories on which consensus had already been reached. After completion of the linking procedure, this resulted in a list of ICF categories for each outcome measure. For those interested, the ICF categories that are linked to a specific outcome measure can be requested from the authors. Putting together all these lists, provides a total list of all ICF categories which are linked to one or

more items in one or more outcome measures. Each outcome measure is used in one or more of the selected studies.

Analyses

Descriptive statistics were used to examine the frequency of application of ICF categories in the selected studies. To gain insight into the ICF categories most frequently addressed in the studies, the frequency of each ICF category was calculated (counting a specific category that appears more than once in a particular study only once). The denominator consists of the total number of studies. We listed all ICF categories that were used in at least 5% of all selected studies in the order of frequency. The level of 5% was chosen because it was in-between the levels used in previous linkage studies [27,28] and follows new recommendations for this kind of study [29]. In any particular study, ICF categories associated at a more specified lower level and a less specified higher level (originating from one or more measures) can be present simultaneously: e.g., pain in upper limb (b28014), pain in body part (b2801) and/or sensation of pain (b280). If the frequency of the lower level is ≤ 5%, we add this to the frequency of the higher level.

The outcome measures are divided into those mainly related to physical health (Table 1) and those mainly related to mental health (Table 2). However, some physical health measures contain some items that refer to mental health, and vice versa. Outcome measures for quality of life are included in the category 'physical health', although some items of these measures are (often) related to mental health.

Measure	Abbreviation	No. of studies	Percentage
Visual analogue scale/Numerical rating scale for pain	VAS/NRS pain	90	73.2%
Neck disability index	NDI	20	16.3%
Short-form health survey with 36 questions	SF-36	12	9.6%
Visual analogue scale/Numerical rating scale for recovery	VAS/NRS recovery	9	7.3%
Nordic questionnaire	NQ	8	6.5%
Visual analogue scale/Numerical rating scale for general functioning	VAS/NRS general functioning	7	5.7%
Neck pain and disability	NPD	6	4.9%
Northwick Park neck pain questionnaire	NPQ	6	4.9%
EuroQol	EQ-5D	5	4.1%
Fear avoidance beliefs questionnaire	FABQ	5	4.1%
Disability of arm, shoulder and hand questionnaire	DASH	4	3.3%
Visual analogue scale/Numerical rating scale for workability	VAS/NRS workability	4	3.3%
Neck and shoulder disability questionnaire	NSDQ	3	2.4%
Numerical rating scale sleep	NRS sleep	3	2.4%
Borg rating of perceived exertion	RPE	2	1.6%
Disability index Rempel/Tittiranonda study		2	1.6%
Pain disability index	PDI	2	1.6%
Short-form health survey with 12 questions	SF-12	2	1.6%
Shoulder pain score	SPS	2	1.6%
Visual analogue discomfort scale	VADS	2	1.6%
West Haven-Yale multidimensional pain inventory	WHYMPI	2	1.6%
Activity discomfort Scale	ADS	1	0.8%
Disability index Croft study		1	0.8%
Disability index Jordan study		1	0.8%
Disability index Viljanen study		1	0.8%
Graded reduced work ability scale	GRWA	1	0.8%
Health assessment questionnaire	HAQ	1	0.8%
Nottingham health profile	NHP	1	0.8%
Numerical rating scale activities of daily living	NRS ADL	1	0.8%
Pain beliefs questionnaire	PBQ	1	0.8%
Short questionnaire to assess health	SQUASH	1	0.8%
Upper extremity function scale	UEFS	1	0.8%
Shoulder pain and disability Index	SPADI	1	0.8%
Subjective health complaints	SHC	1	0.8%
Tiredness scale	TS	1	0.8%
Three questions of the national health interview survey		1	0.8%
Other measure pain *		22	17.9%
Other measure work/sick leave **		20	16.3%
Other measure recovery **		19	15.4%
Other measure disability/Activities of daily living **		16	13.0%

Table 1: Use of measures for physical health in 123 studies on complaints of arm, neck and shoulder (CANS).

* Mostly pain drawing or categorical or ordinal scale; ** Mostly ordinal or categorical scales

As a type of sensitivity analysis we also evaluated the distribution of ICF categories across all ICF-categories that are identified within the outcome measures, including the frequency with which they are applied in the studies. This allowed to compare the frequency of the presence of the ICF categories at study level with the frequency at the level of the applied outcome measures, with regard to measures for both physical and mental health. This additional analysis was performed at the most specified level of the ICF categories, counting each category that appears more than once in a particular measure only once. If a particular ICF category is linked to items of more than one outcome measure, it is counted just as many times. Thus, in this analysis, the denominator consists of the total number of separate ICF categories which are linked to MCs derived from all the outcome measures across all the studies. Because this denominator is ≥ 10 times larger than in the first analysis, we list all ICF categories with a frequency of use of ≥ 0.5% of the total number of ICF categories in order of frequency. If, in case of related ICF categories, the most specified category level reaches a frequency of use of 0.5% or more, this separate category is included. Otherwise, the frequency of this lower level is added to the associated higher level, which is included in the analysis when it is 0.5% or more. Finally, calculation of cumulative frequencies provides insight into the number of ICF categories that make up 50%, 80% or 90% of all ICF categories that are used, and in the total percentage of all ICF categories that are covered by the 10 or 20 ICF categories that are present most often.

Results

The literature search yielded 123 original prognostic and intervention studies (100 clinical trials and 23 cohort studies) [16]. Table 1 presents the measures that address physical health. A simple VAS or NRS for pain is applied in 90 studies, in 30% of these as the only outcome measure. The Neck Disability Index and the 36-item Short Form Health Survey are the most frequently applied measures for physical health (16% and 10% of all studies, respectively). In total, 113 studies (91.9%) report the use of 32 different standardized questionnaires. In addition, a VAS or NRS scale is used 114 times, and another measure for pain or another outcome (mostly an ordinal or categorical scale) 77 times. From all these measures, 487 MCs can be extracted and linked to 167 different ICF categories. Another 23 MCs cannot be linked to specific ICF categories and are registered as pf, nd or nc. Taking into account the number of times the measures are used in the different studies (Table 1), a total of 1773 ICF categories are applied to measure physical health (thus, the mean frequency of application per ICF category is 10.6).

Table 2 presents the measures which address mental health. The Beck Depression Inventory and the Tampa Scale for Kinesophobia are the most frequently applied measures for mental health (28% and 17% of studies that apply mental health measures, respectively). In total, 18 studies (14.6%) report the use of 13 different standardized questionnaires. In addition a VAS or NRS scale is used 6 times, and another measure for coping, self-efficacy, pain beliefs, fear of pain or psychological wellbeing (mostly an ordinal or categorical scale) 5 times. From all these measures, 241 MCs can be extracted and linked to 103 different ICF categories. Another 15 MCs cannot be linked to specific ICF categories and are registered as pf, nd or nc. Taking into account the number of times the measures are used in the different studies (Table 2), a total of 417 ICF categories are applied to measure mental health (i.e., the mean frequency of application per ICF category is 4.0).

Measure	Abbreviation	No. of studies	Percentage
Beck depression inventory	BDI	5	2.8%
Tampa scale for kinesophobia	TSK	3	1.7%
Numerical rating scale for distress	NRS Distress	2	1.1%
Pain coping and cognition list	PCCL	2	1.1%
Spielberger state-trait anxiety scale	STAI-II	2	1.1%
Symptom checklist-90-revised	SCL-90-R	2	1.1%
Visual analogue scale for anxiety	VAS Anxiety	2	1.1%
Arthritis helplessness index	AHI	1	0.6%
Community epidemiologic scale-depression	CES-D	1	0.6%
Depression scale	DEPS	1	0.6%
Four-dimensional complaint list	4DKL	1	0.6%
General health questionnaire	GHQ-28	1	0.6%
Hospital anxiety and depression scale	HADS	1	0.6%
Multidimensional health locus of control questionnaire	MHLC	1	0.6%
Short depression inventory (Rimon's brief depression scale)	SDI	1	0.6%
Visual analogue scale for irritability	VAS Irritability	1	0.6%
Visual analogue scale for depression	VAS Depression	1	0.6%
Other measure self-efficacy **		1	0.6%
Other measure pain beliefs **		1	0.6%
Other measure psychological wellbeing **		1	0.6%
Other measure fear of pain **		1	0.6%
Other measure coping **		1	0.6%

Table 2: Use of measures for mental health in 123 studies on complaints of arm, neck and shoulder (CANS).

** Mostly ordinal or categorical scales.

Table 3 presents the 'top 20' of ICF categories related to physical health, together with the cumulative percentage of all applied ICF categories. (Supplementary Table 1 presents all ICF categories that are used in ≥ 5% of the studies in order of ICF category codes, as well as the frequency of the total number of applied ICF categories).

ICF code	ICF category title	No. of studies	Percentage of studies	Cumulative percentage across all ICF categories categories
b280	Sensation of pain	112	91.1%	10.8%
d850	Remunerative employment	66	53.7%	16.5%
d920	Recreation and leisure	51	41.5%	20.5%
b134	Sleep functions	48	39.0%	23.5%
d510	Washing oneself	45	36.6%	26.5%
d540	Dressing	45	36.6%	29.5%
d640	Doing housework	40	32.5%	32.7%
b152	Emotional functions	36	29.3%	35.2%
d4300	Lifting	36	29.3%	37.5%
d475	Driving	35	28.5%	39.5%
b28010	Pain in head and neck	32	26.0%	41.4%
D	ACTIVITIES AND PARTICIPATION	32	26.0%	43.3%
d230	Carrying out daily routine	30	24.4%	45.3%
d166	Reading	29	23.6%	47.0%
d9205	Socializing	28	22.8%	49.2%
d520	Caring for body parts	26	21.1%	50.8%
s720	Structure of shoulder region	25	20.3%	52.2%
s710	Structure of head and neck region	22	17.9%	53.4%
d9201	Sports	21	17.1%	54.8%
s730	Structure of upper extremity	20	16.3%	56.2%

Table 3: Top 20 of the most often applied ICF categories linked to measures for physical health.

The ICF category 'sensation of pain' is applied most frequently (in 91.1% of studies) and accounts for 10.8% of the total number of ICF categories related to physical health. This is followed by the categories: renumerative employment (5.6%), recreation and leisure (4.0%), sleep functions (3.0%), and washing oneself (3.0%).

The first 10 ICF categories make up about 40% of the total number of applied ICF categories for physical health. The 16 most frequently applied ICF categories (9.6% of total) account for 50%, the 47 most frequently applied ICF categories (28.1% of total) for 80%, and the 65 most frequently applied ICF categories (38.9% of total) for 90%. Of the 16 ICF categories that fall within the 50% margin, 8 (50.0%) refer to specific activities and 3 (18.8%) to participation. For the 80% margin (47 ICF categories) these figures are 25 (53.2%) and 8 (17.0%), respectively.

ICF code	ICF category title	No. of studies	% of studies	No. of times ICF category was applied	Cumulative percentage across all ICF categories
b126	Temperament and personality functions	11	8.9%	13	0.7%
b1300	Energy level	20	16.3%	22	1.2%
b134	Sleep functions	48	39.0%	53	3.0%
b1400	Sustaining attention	22	17.9%	22	1.2%
b152	Emotional functions	36	29.3%	45	2.5%
b265	Touch function	11	8.9%	11	0.6%
b280	Sensation of pain	112	91.1%	192	10.8%
b2801	Pain in body part	12	9.8%	12	0.7%
b28010	Pain in head and neck	32	26.0%	34	1.9%
b28014	Pain in upper limb	7	5.7%	(7)	(0.4%)
b28016	Pain in joints	12	9.8%	12	0.7%
b455	Exercise tolerance functions	8	6.5%	(8)	(0.5%)
b7101	Mobility of several joints	8	6.5%	(8)	(0.5%)
b7603	Supportive functions of arm or leg	10	8.1%	10	0.6%
b840	Sensation related to the skin	13	10.6%	13	0.7%
D	ACTIVITIES AND PARTICIPATION	32	26.0%	34	1.9%
d110	Watching	9	7.3%	9	0.5%
d166	Reading	29	23.6%	30	1.7%
d170	Writing	15	12.2%	15	0.9%
d230	Carrying out daily routine	30	24.4%	36	2.0%
d2302	Completing the daily routine	8	6.5%	(8)	(0.5%)
d3601	Using writing machines	10	8.1%	10	0.6%
d4102	Kneeling	12	9.8%	12	0.7%
d4105	Bending	15	12.2%	15	0.9%
d4150	Maintaining a lying position	11	8.9%	11	0.6%
d4154	Maintaining a standing position	7	5.7%	(8)	(0.5%)
d430	Lifting and carrying objects	14	11.4%	20	1.1%
d4300	Lifting	36	29.3%	41	2.3%
d4301	Carrying in the hands	16	13.0%	18	1.0%
d440	Fine hand use	7	5.7%	13	0.7%
d4401	Grasping	11	8.9%	11	0.6%
d445	Hand and arm use	16	13.0%	26	1.5%
d4452	Reaching	15	12.2%	18	1.0%
d4453	Turning or twisting the hands or arms	7	5.7%	(8)	(0.5%)
d450	Walking	13	10.6%	14	0.8%
d4500	Walking short distances	13	10.6%	13	0.7%
d4501	Walking long distances	12	9.8%	12	0.7%

d4551	Climbing	14	11.4%	14	0.8%
d4552	Running	12	9.8%	12	0.7%
d470	Using transportation	10	8.1%	10	0.6%
d475	Driving	35	28.5%	35	2.0%
d4751	Driving motorized vehicles	8	6.5%	(8)	(0.5%)
d5	Self-care	8	6.5%	(8)	(0.5%)
d510	Washing oneself	45	36.6%	53	3.0%
d520	Caring for body parts	26	21.1%	27	1.5%
d540	Dressing	45	36.6%	54	3.1%
d5400	Putting on clothes	15	12.2%	16	0.9%
d550	Eating	12	9.8%	12	0.7%
d570	Looking after one's health	11	8.9%	13	0.7%
d5702	Maintaining one's health	16	13.0%	17	1.0%
d630	Preparing meals	8	6.5%	10	0.6%
d640	Doing housework	40	32.5%	56	3.2%
d6402	Cleaning living area	7	5.7%	(8)	(0.5%)
d6403	Using household appliances	16	13.0%	17	1.0%
d6505	Taking care of plants, indoors and outdoors	11	8.9%	11	0.6%
d7	Interpersonal interactions and relationships	14	11.4%	14	0.8%
d720	Complex interpersonal interactions	13	10.6%	13	0.7%
d7500	Informal relationships with friends	8	6.5%	(8)	(0.5%)
d760	Family relationships	14	11.4%	15	0.9%
d7702	Sexual relationships	12	9.8%	13	0.7%
d8451	Maintaining a job	17	13.8%	20	1.1%
d850	Remunerative employment	66	53.7%	100	5.6%
d920	Recreation and leisure	51	41.5%	71	4.0%
d9201	Sports	21	17.1%	25	1.4%
d9202	Arts and culture	10	8.1%	10	0.6%
d9205	Socializing	28	22.8%	39	2.2%
s710	Structure of head and neck region	22	17.9%	22	1.2%
s7104	Muscles of head and neck region	8	6.5%	(8)	(0.5%)
s720	Structure of shoulder region	25	20.3%	25	1.4%
s730	Structure of upper extremity	20	16.3%	25	1.4%
e355	Health professionals	9	7.3%	9	0.5%

S Table 1: ICF categories linked to measures for physical health in at least 5% of the studies.

* Parentheses are added when an ICF category did not exceed the threshold of 5% or more of the studies.

Table 4 presents the 'top 20' of ICF categories related to mental health, together with the cumulative percentage of all applied ICF categories. (Supplementary Table 2 presents all ICF categories which are used in ≥ 5% of the studies in order of ICF category codes, as well as the frequency of the total number of applied ICF categories).

ICF code	ICF category title	No. of studies	Percentage of studies	Cumulative percentage across all ICF categories
b152	Emotional functions	17	13.8%	5.5%
b1263	Psychic stability	16	13.0%	10.6%
b1602	Content of thought *	14	11.4%	14.9%
b1265	Optimism *	13	10.6%	18.7%
b1266	Confidence *	12	9.8%	22.5%
b1300	Energy level	12	9.8%	25.7%
b134	Sleep functions	11	8.9%	28.3%
b1470	Psychomotor control *	11	8.9%	31.0%
b4552	Fatiguability	10	8.1%	33.4%
b1302	Appetite *	9	7.3%	35.5%
b1400	Sustaining attention	9	7.3%	37.7%
b280	Sensation of pain	9	7.3%	40.3%
b1264	Openness to experience *	8	6.5%	42.2%
b164	Higher-level cognitive functions *	8	6.5%	44.2%
b340	Alternative vocalization functions *	8	6.5%	46.1%
b6400	Functions of sexual arousal phase *	8	6.5%	48.0%
b130	Energy and drive functions *	7	5.7%	49.0%
b240	Sensations associated with hearing and vestibular function *	7	5.7%	50.4%
b160	Thought functions	6	4.9%	51.1%
d5702	Maintaining one's health	6	4.9%	52.8%

Table 4: Top 20 of the most often applied ICF categories linked to measures for mental health.

* Additional ICF categories compared to analysis of the physical measures.

The ICF category 'emotional functions' (including flattening of affect, lability of emotion, sadness or happiness, love or hate, joy or sorrow, fear, anger, tension or anxiety) is applied most frequently, accounting for 5.5% of the total number of ICF categories related to mental health. This is followed by the categories psychic stability (including an irritable, worried, erratic or moody disposition; 5.1%), content of thought (4.3%), optimism (3.8%), confidence (3.8%) and energy level (3.2%).

The first 10 ICF categories make up about 35% of the total number of applied ICF categories for mental health. The 18 most frequently applied ICF categories (20.5% of total) account for 50%, the 48 most frequently applied ICF categories (54.5% of total) for 80%, and the 63 most frequently applied ICF categories (71.6% of total) account for 90%.

ICF code	ICF category title	No. of studies	% of studies	No. of times ICF category was applied	Cumulative percentage across all ICF categories
b126	Temperament and personality functions	(2)	(1.6%)	6	1.4%
b1262	Conscientiousness	(5)	(4.1%)	6	1.4%
b1263	Psychic stability	16	13.0%	21	5.0%
b1264	Openness to experience	8	6.5%	8	1.9%
b1265	Optimism	13	10.6%	16	3.8%
b1266	Confidence	12	9.8%	16	3.8%
b130	Energy and drive functions	7	5.7%	4	1.0%
b1300	Energy level	12	9.8%	13	3.1%
b1301	Motivation	(3)	(2.4%)	4	1.0%
b1302	Appetite	9	7.3%	9	2.2%
b134	Sleep functions	11	8.9%	7	1.7%
b1342	Maintenance of sleep	(4)	(3.3%)	4	1.0%
b1400	Sustaining attention	9	7.3%	9	2.2%
b1470	Psychomotor control	11	8.9%	11	2.6%
b152	Emotional functions	17	13.8%	23	5.5%
b1521	Regulation of emotion	(5)	(4.1%)	5	1.2%
b1522	Range of emotion	(3)	(2.4%)	3	0.7%
b160	Thought functions	(6)	(4.9%)	3	0.7%
b1602	Content of thought	14	11.4%	18	4.3%
b1603	Control of thought	(5)	(4.1%)	6	1.4%
b164	Higher-level cognitive functions	8	6.5%	8	1.9%
b1644	Insight	(3)	(2.4%)	4	1.0%
b1645	Judgement	(5)	(4.1%)	5	1.2%
b1801	Experience of self and time functions	(3)	(2.4%)	3	0.7%
b240	Sensations associated with hearing and vestibular function	7	5.7%	**	
b2401	Dizziness	**		3	0.7%
b2402	Sensation of falling	**		3	0.7%
b280	Sensation of pain	9	7.3%	11	2.6%
b28010	Pain in head and neck	(5)	(4.1%)	5	1.2%
b28011	Pain in chest	(3)	(2.4%)	3	0.7%
b28013	Pain in back	(3)	(2.4%)	3	0.7%
b340	Alternative vocalization functions	8	6.5%	8	1.9%
b455	Exercise tolerance functions	(3)	(2.4%)	3	0.7%
b4550	General physical endurance	(3)	(2.4%)	3	0.7%
b4552	Fatiguability	10	8.1%	10	2.4%
b460	Sensations regarding cardiovascular/respiratory functions	(3)	(2.4%)	3	0.7%
b535	Sensations associated with the digestive system	(4)	(3.3%)	4	1.0%
b5350	Sensation of nausea	(3)	(2.4%)	3	0.7%
b6400	Functions of sexual arousal phase	8	6.5%	8	1.9%

b760	Control of voluntary movement functions	(3)	(2.4%)	3	0.7%
b765	Involuntary movement functions	(3)	(2.4%)	3	0.7%
D	ACTIVITIES AND PARTICIPATION	(3)	(2.4%)	3	0.7%
d177	Making decisions	(4)	(3.3%)	4	1.0%
d2	General tasks and demand	(4)	(3.3%)	5	1.2%
d230	Carrying out daily routine	(5)	(4.1%)	7	1.7%
d2402	Handling crisis	(2)	(1.6%)	3	0.7%
d4602	Moving around outside the home and other Buildings	(4)	(3.3%)	5	1.2%
d4702	Using public motorized transportation	(3)	(2.4%)	3	0.7%
d570	Looking after one's health	(5)	(4.1%)	3	0.7%
d5701	Managing diet and fitness			5	1.2%
d5702	Maintaining one's health	(6)	(4.9%)	7	1.7%
d7	Interpersonal interactions and relationships	(4)	(3.3%)	4	1.0%
d920	Recreation and leisure	(4)	(3.3%)	4	1.0%
E	ENVIRONMENTAL FACTORS	(5)	(4.1%)	5	1.2%
e3	Support and relationships	(4)	(3.3%)	5	1.2%
e310	Immediate family	(3)	(2.4%)	3	0.7%
e355	Health professionals	(4)	(3.3%)	4	1.0%

S Table 2: ICF categories linked to measures for mental health in at least 5% of the studies.

* Parentheses are added when an ICF category did not exceed the threshold of 5% or more of the studies

** In the first analysis b2401 and b2402 were added under code b240; in the second the third level codes were above 0.5%.

Discussion

Based on the ICF, which provides a common language for functioning and health, it is possible to identify and compare the concepts contained in the numerous generic and condition-specific or location-specific outcome measures used in epidemiological research or clinical trials [26,30]. However, to support implementation of the ICF, practical tools are needed to improve its feasibility [31]. Considering the extent of the ICF (with ≥ 1400 categories) and the need for operationalization and quantification of the ICF categories, the major challenges are: 1) to select those items that are most relevant for specific conditions or healthcare contexts; and 2) linkage of the items of existing measures of health status to the ICF categories [31].

The present study aimed to identify and compare the frequency of ICF categories related to the outcome measures of prognostic and intervention studies, which are used in the scientific evidence for the Dutch multidisciplinary guideline on non-specific CANS. This provides insight into the physical, emotional and social challenges that patients with CANS need to adapt to.

Pain is an important symptom in most patients with CANS; most of the included studies (93%) include one or more measures for pain and, in 27 studies (22%), this is the only outcome measure. Therefore, pain reduction seems to be the main outcome measured in the intervention studies. Participation in work comes second (54% of studies), associated with the work-related nature of various types of CANS and the many work-related items that are incorporated in the applied outcome measures. The recreation and leisure activities come third (42%), suggesting that CANS also has a large impact on participation, apart from work. The fourth place is for sleep functions (39%), which may indicate the impact of sleep disturbance due to musculoskeletal pain. When pain is localized in neck or shoulder, lying on the affected body part can be particular-

ly problematic. Of the physical health measures applied, 11 (38%) have items that are linked to this ICF category (b134), e.g., the Neck Disability Index that is applied in 20 studies. Three studies apply a special NRS for sleep problems.

The perspective of mental health measures in relation to a physical condition is new, although the psychological problems, and the mental health measures used, are not specific for CANS. The present analysis reveals the kinds of mental impairments and the related activities and participation items that are assumed by researchers to play a role in non-specific CANS. Some ICF categories that are linked to the mental health measures also appear after analyzing the physical health measures (e.g., b152: emotional functions), whereas 11 ICF categories are added through analysis of the mental health measures. The number of ICF categories linked to mental health measures that were used in ≥ 5% of all studies is relatively small (18), since measures for mental health were only applied in 14.6% of the studies. Therefore, in the majority of studies, no special attention was paid to mental health outcomes; this implies that, until recently, the impact of CANS on mental health has been underestimated.

The present analysis yields two lists of ICF categories: one related to physical health and one to mental health. They represent the most relevant aspects of functioning and health in relation to non-specific CANS from the perspective of the researchers that conducted those studies. This analysis could serve as a preparatory study for the development of an ICF core set (ICF-CS) for non-specific CANS. The development of core sets started in 2003 [32]. They can be seen as a minimal standard for the assessment and reporting of functioning and health in clinical practice and research, through inclusion of a practical number of the most relevant ICF categories [33]. Currently, over 30 ICF-CSs have been developed. A guide on how to develop an ICF-CS is available, in which the earlier experiences and methods used are incorporated in one protocol [29]. One of the obligatory preparatory studies for an ICF-CS development process is a literature review to identify the aspects of functioning that are described or evaluated in the literature related to the health condition of interest. It is assumed that the researchers select those outcome measures that are considered most relevant for persons with the health condition under consideration. The underlying concepts contained in these measures are identified and linked to ICF categories using established linking rules [24]. After such a review, three additional preparatory studies need to be performed [29].

- An empirical multicenter cross-sectional study to identify the most common problems experienced by persons with non-specific CANS through semi-structured interviews in a clinical setting.
- A qualitative study to identify the most important aspects of functioning, environmental and personal factors through focus groups or semi-structured interviews with persons with non-specific CANS.
- An expert internet-based or Delphi survey to compile expert opinions on aspects of functioning and environmental factors that are relevant for persons with non-specific CANS.

Together with the present study, the preparatory studies can serve as the starting point for a structured decision-making and consensus process at an international conference, during which participating experts (including representatives of patients) can make definite decisions regarding which ICF categories should be included in the ICF-CS for non-specific CANS [29].

The additional analyses at the level of the outcome measures are conducted to gain more insight into the relative importance of the ICF categories. It appears that with a threshold for selecting ICF categories with a frequency of use of ≥ 0.5%, the resulting list of candidate ICF categories is almost the same as in the first analysis. This means that the list of ICF categories is a good representation of the MCs that are present in the measures that were applied in the research projects of the systematic review. However, 72 ICF categories are above this threshold, of which 32 have a frequency of less than 10% of the studies and 26 have less than 9%. With 47 ICF categories, 80% of all ICF categories incorporated in all the outcome measures (second analysis) are covered; this 80% corresponds to a threshold of about 9% of studies in which a particular ICF category is applied.

In the additional analysis, outcome measures for mental health are analyzed separately. The frequency of many more categories exceeds the threshold of 0.5% (see Supplementary Table 2), because the denominator is related to the actual use of mental health measures.

In order to compile a list of the most relevant ICF categories for a particular condition, it can be discussed whether truncation at the second level of the ICF categories should be performed before making the selection. The ICF-CS development guide suggests to only include a third or fourth level ICF category if the additional specification yielded by that category is essential to comprehensively describe the functioning of persons with the condition of interest [29]. In the present study the more specified levels are also included, in order to avoid losing any information that is specific to (for instance) hand or shoulder function.

An ICF-CS for hand conditions is available and has considerable overlap with the list of ICF categories in the present study [34]. Almost 40% of the body functions not related to skin conditions or tactile functions, and almost 60% of the activities and participation items of the ICF-CS for hand conditions, are also in the list of ICF categories linked to physical measures for CANS. Vice versa: from the present list about two thirds of the ICF categories for bodily functions and 75% of those for activities and participation, are also included in the ICF-CS for hand conditions.

Study Limitations

For the present study the literature search covered the period 1995 until May 2010 and was performed in Medline and Embase. Only articles in English, German or Dutch on prognostic and intervention studies were included. No additional search was performed for more recent studies, or for studies in other languages or with other designs. However, this is not a serious disadvantage given the purpose of our study. For that, a representative set of articles is needed, from which the outcome measures can be extracted. Through analysis of the outcome measures applied in 123 studies, 72 ICF categories were found that are assumed to be the most relevant for physical health in patients with CANS and 57 for mental health, covering about 90% of all ICF categories incorporated in all the outcome measures (second analysis). It is unlikely that outcome measures applied in more recent years, or included in articles in other languages, would substantially change these results.

The aim of the present study was to analyze the ICF categories that are most relevant for non-specific CANS. This is not because a large difference is assumed in the perceived importance of aspects of functioning and health between non-specific and specific CANS, but simply the practical consequence of using a literature search made for the development of the guideline, which made a selection of studies on non-specific CANS. However, for some specific CANS (e.g., hand disorders or arthritis) the frequency of some specific functions or activities can differ slightly; nevertheless, most items in the lists seem to be equally relevant to both non-specific and specific CANS.

In this study, a distinction is made between outcomes for physical health and mental health, because psychological factors are assumed to be important for patients with CANS but are only measured as an outcome in 15% of the included studies. This low percentage may be because measures for mental health have more often been studied as a prognostic or confounding factor, rather than a relevant health outcome.

Conclusions

This study has identified aspects of functions, activities and participation in outcome measures used in research on CANS and linked them to the ICF, based on the literature that was included in the multidisciplinary guideline for non-specific CANS. This study can serve as the first preparatory study for the development of an ICF-CS for CANS.

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