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ICF CORE SETS FOR DEPRESSION

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Objective: **To report on the results of the consensus process integrating evidence from preliminary studies to develop the first version of a *Comprehensive ICF Core Set* and a *Brief ICF Core Set* for depression.**

Methods: **A formal decision-making and consensus process integrating evidence gathered from preliminary studies was followed. Preliminary studies included a Delphi exercise, a systematic review and an empirical data collection. After receiving training in the ICF and based on these preliminary studies, relevant ICF categories were identified in a formal consensus process by international experts from different backgrounds.**

Results: **The preliminary studies identified a set of 323 ICF categories at the second, third and fourth ICF levels with 163 categories on *body functions*, 22 on *body structures*, 91 on *activities and participation* and 47 on *environmental factors*. Twenty experts attended the consensus conference on depression. Altogether 121 categories (89 second-level and 32 third-level categories) were included in the *Comprehensive ICF Core Set* with 45 categories from the component *body functions*, 48 from *activities and participation* and 28 from *environmental factors*. The *Brief ICF Core Set* included a total of 31 categories with 9 on *body functions*, 12 on *activities and participation* and 10 on *environmental factors*.**

Conclusion: **A formal consensus process integrating evidence and expert opinion based on the ICF framework and classification led to the definition of *ICF Core Sets* for depression. Both the *Comprehensive ICF Core Set* and the *Brief ICF Core Set* were defined.**

Key words: depression, mood disorders, depressive disorders, outcome assessment, quality of life, ICF.

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INTRODUCTION

Depression is a mood disorder characterized by sadness, loss of interest in activities and decreased energy. Other symptoms include loss of confidence and self-esteem, inappropriate guilt, thoughts of death and suicide, diminished concentration and disturbance of sleep and appetite. A variety of somatic symptoms may also be present (1, 2). Depression is associated with significant loss of quality of life (3, 4), increased morbidity and mortality (5–7) and enormous economic burden, the largest component of which derives from lost work productivity (8). Global Burden of Disease analysis shows that unipolar depressive disorders are ranked as the fourth leading cause of burden among all diseases (1). Depression accounts for 4.4% of the total Disability Adjusted Years (DALYs) and is the leading cause of Years Lived with Disability (YLD), accounting for 11.9% of total YLDs. By the year 2020, the burden of depression is expected to increase to 5.7% of the total burden of disease, becoming the second leading cause of DALYs lost. Worldwide it will be second only to ischaemic heart disease for DALYs lost for both sexes. If current trends for demographic and epidemiological transition continue, depression will be the highest ranking cause of burden of disease in the developed regions (1).

Functioning is increasingly taken into account for the diagnoses of depression as well as for evaluating the effectiveness of treatments.

The American Psychiatric Association included the concept of functioning as diagnostic option for assessing major depressive disorder or dysthymic disorder in the fourth edition of its Diagnostic and Statistical Manual of Mental Disorders (9).

Current recommendations refer to remission as the optimal outcome of treatment of depression (10). Although there is no universally accepted definition for remission, remission criteria are currently primarily based on a significant reduction in the number and severity of symptoms and patients functioning (10). The assessment of a significant reduction in symptoms is typically based on scores of symptomatic rating scales, such as the Hamilton Rating Scale for Depression (11) or the Montgomery Asberg Depression Rating Scale (12). However, there is considerable uncertainty about the relevant domains of functioning and how to measure them.

Studies which evaluate psychosocial adjustment (13, 14), quality of life (15–17), work functioning (18–21), and social

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functioning (20, 22, 23) have been performed using a number of different generic measures, like the Short Form-36 (SF-36) (24), the Sickness Impact Profile (SIP) (25), the Social Adjustment Scale (SAS) (26) and the Quality of Well-Being Scale (QWB) (27), as well as a number of condition-specific instruments, such as the Quality of Life in Depression Scale (28), the Social Adaptation Self-Evaluation Scale (29), the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) (30), and the Depression-Specific Quality-of-Life Battery (DQOLB) (16). Nevertheless, all these measures vary quite considerably regarding the domains of functioning included (3).

It is also important to recognize that depressive disorders are most often reported to and managed by primary-care physicians (31). In light of increasing patient demands and the limited time and resources available to primary-care doctors, the use of such measures to evaluate remission in patients with depression is almost impossible.

It would, therefore, be valuable to have a practical tool that covers the spectrum of symptoms and limitations in functioning of patients with depression.

With the approval of the new International Classification of Functioning, Disability and Health (ICF, formerly ICIDH-2 (ICF, formerly ICIDH-2 http://www.who.int/classification/icf) (32), one can now rely on a globally agreed framework and classification to define the typical spectrum of problems in functioning of patients with depression. Based on the ICF generally-agreed-on list of ICF categories can be defined. Such lists can serve as *Brief ICF Core Set* to be rated in all patients included in a clinical study with depression or as *Comprehensive ICF Core Set* to guide multidisciplinary assessments in patients with depression. The objective of this paper is to report on the results of the consensus process integrating evidence from preliminary studies to develop the first version of both *ICF Core Sets* for depression, the *Comprehensive ICF Core Set* and the *Brief ICF Core Set*.

METHODS

The development of the *ICF Core Sets* for depression involved a formal decision-making and consensus process integrating evidence gathered from preliminary studies, including a Delphi exercise (33), a systematic review (34) and an empirical data collection, using the ICF checklist (35). After training in the ICF and based on these preliminary studies, relevant ICF categories were identified in a formal consensus process by international experts from different backgrounds.

Twenty experts from 8 different countries attended the consensus process for depression. The professional background of the experts (6 psychiatrists, 6 physicians with at least a specialization in physical and rehabilitation medicine, 4 psychologists, 2 physical therapists, one nurse and one occupational therapist) covered the wide spectrum of limitations in functioning that occurs in patients with depression. The decision-making process for depression involved 3 working groups, 2 with 5 and one with 6 experts, respectively. The process was facilitated by the condition co-ordinator for depression (RB) and the 3 working-group leaders (PC, MH and JM).

RESULTS

The final cut-off vote to define the final number of categories to be included in the Brief ICF Core Set was not performed for the health condition depression, since 8 participants left the conference prematurely. Nevertheless, since the experts were requested in 2 ranking exercises to individually rank in order of importance for each ICF component a maximum of 15 ICF categories of the *Comprehensive ICF Core Set* to be included in the *Brief ICF Core Set*, the ranking exercises themselves represented a selection of categories to form the *Brief ICF Core Set.*

The tables on the preliminary studies (33–35) presented to the participants included 323 ICF categories at the second, third and fourth levels (163 on *body functions*, 22 on *body structures*, 91 on *activities and participation* and 47 on *environmental functions*).

Tables I–III show the second- and third-level ICF categories included in the *Comprehensive ICF Core Set*. Table IV shows the second- and third-level ICF categories selected for the *Brief ICF Core Set*, as well as the rank order by component allotted to the ICF categories in the second ranking exercise.

Comprehensive ICF Core Set

The number of second- and third-level categories in the *Comprehensive ICF Core Set* is 121, with 89 categories at the second level and 32 categories at the third level. The 32 third-level categories constitute a further specification of 9 categories on the second level.

The 121 categories of the *Comprehensive ICF Core Set* are made up of 45 (37%) categories from the component *body functions*, 48 (40%) from the component *activities and participation* and 28 (23%) from the component *environmental factors*. No categories from the component *body structures* are included in the Comprehensive ICF Core Set.

Seventeen of the 45 categories of the component *body functions* are at the second level. They represent 12% of the total number of ICF categories at the second level in this component. Twenty-eight of the 45 categories are at the third level of the classification, all of which belong to chapter 1 *mental functions*. Thus, chapter 1 *mental functions* is the chapter within the component *body functions* with the greatest number of categories included (39 categories). The 28 third-level categories are specifications of the second-level categories b126 *temperament and personality functions*, b130 *energy and drive functions*, b134 *sleep functions*, b152 *emotional functions*, b160 *thought functions*, b164 *higher-level cognitive functions* and b180 *experience of self and time functions*. Chapter 5 *function of the digestive, metabolic and endocrine systems* is represented by 2 categories. Chapter 2 *sensory functions and pain*, chapter 4 *functions of the cardiovascular, haematological, immunological and respiratory systems*, chapter 6 *genitourinary and reproductive functions* and chapter 7 *neuromusculoskeletal and movement-related functions* are all represented by one category only.

Forty-five of the 48 categories of the component *activities and participation* are at the second, and 3 categories are at the third level of the classification. The 45 categories at the second level represent 38% of the total number of ICF categories at the

Table I. *International Classification of Functioning, Disability and Health (ICF) categories of the component body functions included in the Comprehensive ICF Core Set for Depression*

ICF code		ICF category title
2nd level	3rd level	
b117		Intellectual functions
b126		Temperament and personality functions
	b1260	Extraversion
	b1261	Agreeableness
	b1262	Conscientiousness
	b1263	Psychic stability
	b1265	Optimism
	b1266	Confidence
b130		Energy and drive functions
	b1300	Energy level
	b1301	Motivation
	b1302	Appetite
	b1304	Impulse control
b134		Sleep functions
	b1340	Amount of sleep
	b1341	Onset of sleep
	b1342	Maintenance of sleep
	b1343	Quality of sleep
	b1344	Functions involving the sleep cycle
b140		Attention functions
b144		Memory functions
b147		Psychomotor functions
b152		Emotional functions
	b1520	Appropriateness of emotion
	b1521	Regulation of emotion
	b1522	Range of emotion
b160		Thought functions
	b1600	Pace of thought
	b1601	Form of thought
	b1602	Content of thought
	b1603	Control of thought
b164		Higher-level cognitive functions
	b1641	Organization and planning
	b1642	Time management
	b1644	Insight
	b1645	Judgement
b180		Experience of self and time functions
	b1800	Experience of self
	b1801	Body image
b280		Sensation of pain
b460		Sensations associated with cardiovascular and respiratory functions
b530		Weight maintenance functions
b535		Sensations associated with the digestive system
b640		Sexual functions
b780		Sensations related to muscles and movement functions

Table II. *International Classification of Functioning, Disability and Health (ICF) categories of the component activities and participation included in the Comprehensive ICF Core Set for Depression*

ICF code		ICF category title
2nd level	3rd level	
d110		Watching
d115		Listening
d163		Thinking
d166		Reading
d175		Solving problems
d177		Making decisions
d210		Undertaking a single task
d220		Undertaking multiple tasks
d230		Carrying out daily routine
	d2301	Managing daily routine
	d2302	Completing the daily routine
	d2303	Managing ones own activity level
d240		Handling stress and other psychological demands
d310		Communicating with – receiving – spoken messages
d315		Communicating with – receiving – non-verbal messages
d330		Speaking
d335		Producing non-verbal messages
d350		Conversation
d355		Discussion
d470		Using transportation (car, bus, train, plane, etc.)
d475		Driving (riding bicycle and motorbike, driving car, riding animals, etc.)
d510		Washing oneself
d520		Caring for body parts
d540		Dressing
d550		Eating
d560		Drinking
d570		Looking after ones health
d620		Acquisition of goods and services
d630		Preparing meals
d640		Doing housework
d650		Caring for household objects
d660		Assisting others
d710		Basic interpersonal interactions
d720		Complex interpersonal interactions
d730		Relating with strangers
d750		Informal social relationships
d760		Family relationships
d770		Intimate relationships
d830		Higher education
d845		Acquiring, keeping and terminating a job
d850		Remunerative employment
d860		Basic economic transactions
d865		Complex economic transactions
d870		Economic self-sufficiency
d910		Community life
d920		Recreation and leisure
d930		Religion and spirituality
d950		Political life and citizenship

second level in this component. All 9 chapters of this component are represented in the *Comprehensive ICF Core Set*.

Chapter 2 *general tasks and demands* is the chapter with the highest number of categories included (7 categories), whereas 3 of them are specifications of the second-level category d230 *carrying out daily routine*. Chapter 1 *learning and applying knowledge*, chapter 3 *communication*, chapter 5 *self-care*, chapter 7 *interpersonal interactions and relationships*, and chapter 8 *major life areas* are each represented by 6 categories. Chapter 6 *domestic life*, chapter 9 *community, social and civic life* and chapter 4 *mobility* are represented by 5, 4 and 2 categories, respectively.

Twenty-seven of the 28 categories of the component *environmental factors* are at the second level in the ICF hierarchy. They represent 36% of the total number of ICF categories at the second level of this component. Most of the

Table III. *International Classification of Functioning, Disability and Health (ICF) categories of the component environmental factors included in the Comprehensive ICF Core Set for Depression*

ICF code		ICF category title
2nd level	3rd level	
	e1101	Drugs
e165		Assets
e225		Climate
e240		Light
e245		Time-related changes
e250		Sound
e310		Immediate family
e320		Friends
e325		Acquaintances, peers, colleagues, neighbours and community members
e330		People in positions of authority
e340		Personal care providers and personal assistants
e355		Health professionals
e360		Health-related professionals
e410		Individual attitudes of immediate family members
e415		Individual attitudes of extended family members
e420		Individual attitudes of friends
e425		Individual attitudes of acquaintances, peers, colleagues, neighbours and community members
e430		Individual attitudes of people in positions of authority
e440		Individual attitudes of personal care providers and personal assistants
e450		Individual attitudes of health professionals
e455		Individual attitudes of health-related professionals
e460		Societal attitudes
e465		Social norms, practices and ideologies
e525		Housing services, systems and policies
e570		Social security services, systems and policies
e575		General social support services, systems and policies
e580		Health services, systems and policies
e590		Labour and employment services, systems and policies

environmental-factors categories belong to chapter 4 *attitudes* (10 categories). All 5 chapters of this component are represented in the Comprehensive ICF Core Set. Chapter 3 *support and relationships*, chapter 5 *services, systems and policies* and chapter 2 *natural environment and human-made changes to environment* are represented by 7, 5 and 4 second-level categories, respectively. Chapter 1 *products and technology* is represented by 2 categories, one at the second and the other at the third level of the classification.

Brief ICF Core Set

The *Brief ICF Core Set* includes a total of 21 second-level categories and 10 third-level categories which represent 26% of all ICF categories that were chosen in the *Comprehensive ICF Core Set*. Nine ICF categories were chosen from the component *body functions* (representing 20% of selected second-level categories in the *Comprehensive ICF Core Set*), 12 from *activities and participation* (representing 25% of selected second-level categories in the Comprehensive ICF Core Set) and 10 from *environmental factors* (representing 36% of selected second-level categories in the *Comprehensive ICF Core Set*).

DISCUSSION

The formal consensus process integrating evidence from preliminary studies and expert knowledge at the third ICF Core Sets conference led to the definition of the *Comprehensive ICF Core Set* for multidisciplinary assessment and the *Brief ICF Core Set.*

A main challenge during the decision-making and consensus process was to avoid the diagnostic perspective of depression in favour of a broader perspective to describe the whole experience of functioning and disability of patients with depression. Therefore, it is not surprising that the overlap between ICD, which reflects the diagnostic perspective, and the ICF, which reflects a broader perspective of functioning and health, was an issue explicitly discussed in the group of experts on depression.

The *Comprehensive ICF Core Set* for depression is the second largest (after stroke) among the 12 *Comprehensive ICF Core Sets* developed for the most burdensome chronic conditions. The fact that 121 categories were included in the *Comprehensive ICF Core Set* reflects the importance of and complex limitations in functioning and the numerous interactions with environmental factors relevant in patients with depression.

No category from the component *body structures* was selected. The inclusion of the category s110 *structure of the brain* was discussed among the different experts. At the end of a long discussion, they decided that the brain is a relevant body structure, but not an indispensable body structure to comprehensively describe the functioning and health of patients with depression. The *structure of the brain* was, therefore, not included in the *ICF Core Sets*.

Since depression is a mental disorder, it is not surprising that most of the functions selected within the component *body functions* are mental functions. Many of them are at the third level of the classification, showing that with regard to the mental functions both a broad conceptual and an in-depth understanding are required when addressing functioning and health of patients with depression.

Body functions, such as pain, sensations associated with cardiovascular, respiratory, digestive, muscular and movement functions, as well as weight maintenance and sexual functions, were also considered sufficiently relevant to be included in a multidisciplinary, comprehensive assessment and hence in the *Comprehensive ICF Core Set*.

Limitations and restrictions in *activities and participation* may, indeed, be most relevant to patients with depression. This is reflected not only by the fact that 48 categories of this component have been included, but also by the fact that all nine chapters of this component are represented in the *Comprehensive ICF Core Set*. Based on this result, it can be concluded that the group of experts participating in the conference considered

Table IV. *International Classification of Functioning, Disability and Health (ICF) categories ranked in the second ranking exercise to select the categories of the Brief ICF Core Set for depression as well as rank allotted to each category*

ICF component	Rank order	ICF code	ICF category title
Body functions	1	b1263	Psychic stability
	2	b1300	Energy level
	3	b1301	Motivation
	4	b1522	Range of emotion
	5	b1265	Optimism
	6	b140	Attention functions
	7	b1521	Regulation of emotion
	8	b1302	Appetite
	9	b147	Psychomotor functions
Activities and participation	1	d2301	Managing daily routine
	2	d177	Making decisions
	3	d175	Solving problems
	4	d770	Intimate relationships
	5	d240	Handling stress and other psychological demands
	6	d760	Family relationships
	7	d350	Conversation
	8	d570	Looking after ones health
	8,5	d163	Thinking
	9	d510	Washing oneself
	10	d2303	Managing ones own activity level
	10	d845	Acquiring, keeping and terminating a job
Environmental factors	1	e310	Immediate family
	2	e320	Friends
	3	e355	Health professionals
	4	e1101	Drugs
	5	e410	Individual attitudes of immediate family members
	6	e325	Acquaintances, peers, colleagues, neighbours and community members
	7	e420	Individual attitudes of friends
	8	e580	Health services, systems and policies
	9	e450	Individual attitudes of health professionals
	10	e415	Individual attitudes of extended family members

the full range of life areas included in the ICF classification as affected in patients with depression. Beside the life areas, such as work, relationships with family and friends and "recreation and leisure", which have been widely reported in the literature as areas affected by depression (3), other issues less frequently reported in the literature such as self-care (dressing, eating, drinking, washing oneself), mobility and religion were considered relevant and therefore selected.

It is remarkable that all chapters of the component *environmental factors* are represented in the *Comprehensive ICF Core Set*. The 28 *environmental-factors* categories, constituting 23% of the categories of the *Comprehensive ICF Core Set*, represent aspects of the physical, social and attitudinal environment of patients with depression.

The chapter *attitudes* represents more than one-third of the total number of *environmental factors* included. This may reflect the high impact that the attitudes of the *significant others*, as well as the attitudes of society in general, can have on patients with depression. Persons suffering from mental and behavioural disorders still face stigma and discrimination in all parts of the world, thereby crucially influencing their individual behaviour, social life, general functioning and recovery (1).

The relevance of mental health policy and service provision was discussed and recognized in the depression group. Five categories of the chapter *services, systems and policies* were thus included in the *Comprehensive ICF Core Set*. The high importance of the *support and relationships* from "significant others" for patients with depression is also reflected in the number of selected categories within this chapter. New directions in the treatment of patients with depression emphasize the need to involve the family or "significant others" in the treatment process (36–38). In the *Comprehensive ICF Core Set*, the relevance of pharmacological therapy in depression, as well as the influence of factors of the natural environment, is also reflected by the inclusion of the categories *drugs*, *climate*, *light*, and *time-related changes* and *sound*.

Regarding the comprehensiveness of the ICF, it is most interesting to note that the panel of experts wanted to include an ICF category to address suicide but such a category is not contained in the ICF. Since Mood disorders, most often clinical depression, are found in as many as 90% of completed suicides (39), such a category needs to be addressed in clinical studies and multidisciplinary assessments of patients with depression. Thus, the inclusion of a category addressing suicide should be considered in possible future revisions of the ICF. In addition, suicide is to be considered in the validation and testing studies of the *ICF Core Sets*.

It is important to recognize that the *Comprehensive ICF Core Set* with its 121 categories is still too long for different clinical settings, such as primary care. This emphasizes the

importance of the extensive validation and testing of this first version of the *Comprehensive ICF Core Set* from the perspectives of different professions, in different clinical settings and in different countries.

The *Brief ICF Core Set* represents a far narrower view, focusing on the most important chapters and categories for the different components. Nevertheless, since no final vote was performed to define a final number of categories to be included in the *Brief ICF Core Set* in the depression group, extensive validation and testing of the *Comprehensive ICF Core Set* is also required to achieve a definitive *Brief ICF Core Set* that can then be compared with the results of the ranking exercise from the conference.

Irrespective of the fact that the organizers of the consensus process took much care in the selection of the experts and were successful in recruiting 20 experts with different professional backgrounds from 8 different countries, the results of any consensus process may differ with different groups of experts.

For all the above-mentioned reasons, the first version of the *ICF Core Sets* is only recommended for validation or pilot studies.

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