International Classification of Functioning, Disability and Health (ICF) Core Set for patients with acute arthritis

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Abstract

Objective

The aim of this consensus process was to construct a preliminary version of the ICF Core Set for acute inflammatory arthritis.

Methods

The development of the ICF Core Set involved a formal decision-making and consensus process, integrating evidence gathered from preliminary studies including focus groups of health professionals, a systematic review of the literature, and empiric data collection from patients.

Results

Thirty-three experts selected a total of 79 second-level categories for the Comprehensive Core Set and 40 second-level categories for the Brief Core Set. The largest number of categories was selected from the ICF component Activities and Participation (28 categories or 35%). Eighteen (23%) of the categories were selected from the component Body Functions, 13 (16%) from the component Body Structures, and 20 (25%) from the component Environmental Factors.

Conclusion

The ICF Core Set for acute arthritis is a clinical framework designed to comprehensively assess patients in acute care hospitals and early post-acute rehabilitation facilities. This preliminary version of the ICF Core Set will be further tested through empiric studies in German-speaking countries and internationally.

Key words

Rheumatic diseases, rehabilitation, acute rehabilitation, ICF, ICF Core Sets.

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Introduction

Acute inflammatory arthritides such as rheumatoid arthritis, psoriatic arthritis and crystal-associated disease can be grouped together as predominantly peripheral joint diseases characterized by significant joint pain, joint swelling and stiffness and varying degrees of loss of body functions. Such acute impairments in body functions have a major impact on physical activities (1) and cause significant restrictions in a patient's participation in daily life activities (2). Without adequate treatment these inflammatory arthritides, affecting patients in their most productive years (3), can progress to joint destruction and significant longer-term disability (4, 5) in terms of bodily impairments, activity limitations and participation restrictions.

Optimal acute patient care comprises a wide range of therapeutic interventions directed towards both the relief of symptoms and the prevention of disease progression and structural damage. Even in the acute state, management is not only directed at maintaining and restoring current functioning but also at preventing long-term disability. Equally, interventions are aimed at the patient's environment in order to facilitate participation and adjustment to the chronic disease state (6).

Physicians and other health professionals caring for patients with acute inflammatory arthritis should be able to recognize and communicate the patient's needs and functional status and the common goals of multi-disciplinary therapy (7, 1). It is therefore important and valuable to define what must be measured in order to best represent the patients' experience in acute arthritis. Current outcome measures used in clinical trials either ignore functional status by focusing on symptom severity alone or cover only selected aspects of functioning, neglecting in particular participation and environmental issues (8); this seems to be an incomplete approach when dealing with multi-disciplinary patient care.

The International Classification of Functioning, Disability and Health (ICF) is the newest member of the World Health Organization (WHO) family of international classifications, and is designed to record and organize a wide range of information about health and health-related states (9). The ICF categories facilitate the description and classification of all aspects of function and health in individuals, independently of the disease or specific measurement instruments. It is important to separate the assessment of disease and disability dimensions, but at the same time to employ these constructs jointly using both the International Classification of Diseases (ICD) and the ICF.

The ICF analyzes functioning in relation to a health condition in terms of: (1) body functions and body structures, (2) activities of the person and participation of the person in the society, and (3) contextual factors such as environmental factors and personal factors. The separation of signs/symptoms and consequences permits a better understanding of the disease pathophysiology and the consequences of disease. With over 1,400 categories ICF provides a complete and detailed classification of functioning and disability, but not every user of the ICF will require the range and detail that it provides. Clinicians, for example, who wish to apply ICF's bio-psycho-social model to their daily practice will require only a fraction of the categories found in the ICF. For most clinical uses, indeed, as few as 20% of the categories will explain more than 80% of the variation observed in practice. It is therefore necessary to identify those components of the ICF that are relevant to specific patient groups, with respect to both the disease state and disease activity.

The ICF Core Sets are intended to respond to this need. ICF Core Sets have already been developed for patients with acute (10) and chronic disease (11). Specific Core Sets have also recently been proposed to describe acute and early post-acute musculoskeletal conditions (12, 13), chronic rheumatoid arthritis (14), and osteoarthritis (15). They are not specifically designed for the specialised comprehensive rheumatologic care of patients with acute arthritis, however. The ICF Core Set for rheumatoid arthritis was developed from the perspective of a chronic con-

dition and therefore does not address the specific needs of the acute situation, such as knowledge about potentially life-threatening impairments. At the same time it includes aspects that do not require attention in the acute situation. In contrast, the acute ICF Core Set for musculoskeletal conditions was developed for non-specialised services in acute care hospitals and therefore does not address the needs of specialised comprehensive services that provide both acute and rehabilitation care, as is typical of the acute rheumatologic services in Germany. Finally, the early post-acute ICF Core Set for musculoskeletal conditions, which is intended for rehabilitation services providing care for a wide range of musculoskeletal conditions including arthritis, does not specifically address the needs of patients with acute arthritis. It may thus be expected that the spectrum of ICF categories relevant for the comprehensive specialised care of patients with acute arthritis will differ from the already developed ICF Core Sets.

Currently there is no agreement in the literature with regard to the issues most relevant to the care of patients with acute arthritis in specialised rheumatologic services. From the user's perspective it is therefore time to develop an ICF Core Set for acute arthritis. This development could also contribute to the process of validating the already developed early post-acute ICF Core Set for musculoskeletal conditions.

The aim of this consensus process was to decide on the preliminary ICF Core Sets for acute inflammatory arthritis, integrating evidence from preliminary studies and input from experts in the field.

Materials and methods

The development of the ICF Core Sets for patients with acute arthritis involved a formal decision-making and consensus process integrating evidence gathered from preliminary studies including focus groups of health professionals (16), a systematic review of the literature (8) and empiric data collection from patients (17).

In this process both a Brief ICF Core Set and a Comprehensive ICF Core Set were established. The Brief ICF Core Set is intended to rate all patients included in a clinical study or an epidemiological study, and the Comprehensive ICF Core Set to guide multidisciplinary assessments. A Brief ICF Core Set for a specific condition must include as few categories as possible to be practical, but as many as are necessary to be sufficiently comprehensive and describe the typical spectrum of functional problems in patients with a specific condition. In this way it can be of use in clinical trials or even in everyday clinical practice, as in clinical reports.

The consensus process has been described in detail elsewhere, relating to the development of the ICF Core Sets for acute care hospitals and early post-acute rehabilitation facilities (10).

After training in the ICF, the participants in the conference identified those ICF categories considered to be relevant to patients with acute arthritis. The participants were chosen, based on their expertise in the management of acute arthritis, from specialized acute rheumatology clinics and hospitals throughout Germany. The German patients' society for rheumatic diseases (Deutsche Rheuma-Liga Bundesverband) and the institutions involved in the preliminary studies were also asked to nominate delegates. Throughout the process the participants were advised that their decisions should always be based on the results of the preliminary studies and the participants' clinical experience and expertise. For the purposes of this study, patients with acute arthritis were defined as persons suffering from

Table I. The International Classification of Functioning, Disability and Health (ICF) – categories from the component Body Functions included in the Comprehensive and Brief ICF Core Sets for patients with acute arthritis. Votes A, B, and C indicate the stage of the consensus process during which a category was selected (votes A and B were made by the working groups, while vote C was taken during the final plenary session).

ICF code	Category description	Vote	Brief Core Set
	Chapter: Mental functions (4 categories selected out of 22 chapter categories)		
b126	Temperament and personality functions	A	x
b130	Energy and drive functions	B	x
b134	Sleep functions	A	x
b152	Emotional functions	C	x
	Chapter: Sensory functions and pain (1 category selected out of 18 chapter categories)		
b280	Sensation of pain	A	x
	Chapter: Functions of cardiovascular, haematological, immunological and respiratory systems (5 categories selected out of 16 chapter categories)		
b415	Blood vessel functions	B	x*
b430	Haematological system functions	B	x*
b435	Immunological system functions	A	x
b440	Respiration functions	C	x*
b455	Excercise tolerance functions	C	x*
	Chapter: Neuromusculosceletal and movement-related functions (8 categories selected out of 17 chapter categories)		
b710	Mobility of joint functions	A	x
b715	Stability of joint functions	A	x
b720	Mobility of bone functions	A	
b730	Muscle power functions	A	x
b735	Muscle tone functions	B	
b740	Muscle endurance functions	C	
b770	Gait pattern functions	A	
b780	Sensations related to muscles and movement functions	B	x

*to be considered in extra-articular manifestations of disease.

Table II. The International Classification of Functioning, Disability and Health (ICF) – categories from the component Body Structures included in the Comprehensive and Brief ICF Core Sets for patients with acute arthritis. Votes A, B, and C indicate the stage of the process during which a category was selected (votes A and B were made by the working groups, while vote C was taken during the final plenary session).

ICF code	Category description	Vote	Brief Core Set
	Chapter: The eye, ear and related structures (2 categories selected out of 8 chapter categories)		
s220	Structure of the eyeball	C	x
s230	Structures around the eye	C	
	Chapter: Structures of the cardiovascular, immunological and respiratory systems (2 categories selected out of 5 chapter categories)		
s420	Structure of the immune system	C	
s430	Structure of the respiratory system	C	
	Chapter: Structures related to movement (7 categories selected out of 9 chapter categories)		
s710	Structure of the head and neck region	B	x
s720	Structure of the shoulder region	A	x
s730	Structure of the upper extremity	A	x
s740	Structure of the pelvic region	A	x
s750	Structure of the lower extremity	A	x
s760	Structure of the trunk	B	x
s770	Additional musculoskeletal structures related to movement	A	x
	Chapter: Skin and related structures (2 categories selected out of 6 chapter categories)		
s810	Structure of areas of skin	B	x
s830	Structure of the nails	C	

a new-onset inflammatory arthritis involving two or more peripheral joints (not including the hips, sacro-iliac or axial joints), or an acute flare of known inflammatory arthritis involving new inflammation of two or more peripheral joints, of a maximum 8 weeks duration. The participants were instructed not to take into consideration problems associated with co-morbidities, complications or drug-related events.

The decision-making process consisted of two major parts. In the first part the Comprehensive ICF Core Set was developed according to the definition given above. The experts discussed and made their decisions in three working groups, split by health profession (vote A). The results of vote A were then presented to all the experts at a plenary session. After the plenary discussions, further discussions took place in the working groups and a second decision was made (vote B). The results of vote B were then presented and discussed at a second plenary session, and the final decision (vote C) was made. In the second part of the decision-making process, the experts were asked to select categories from the Comprehensive ICF Core Set that they considered essential for inclusion in the Brief ICF Core Set.

Results

Thirty-three experts participated in the consensus process. The groups consisted of ten physicians, six physiotherapists, four occupational therapists, nine nurses, three psychologists and a patient representative from the German league against rheumatism. The process was coordinated by a clinical epidemiologist (EG). Each working group was guided by a working group leader. The resulting ICF Core Set included a total of 79 second-level categories. The largest number of categories was selected from the ICF component Activities and Participation (28 categories or 35%). Eighteen (23%) of the categories were selected from the component Body Functions, 13 (16%) from the component Body Structures, and 20 (25%) from the component Environmental Factors.

The Brief ICF Core Set contained 40 categories, 14 categories from the component Body Functions, 9 categories from the component Body Structures, 10 categories from the component Activities and Participation, and 7 categories from the component Environmental Factors. The experts included four categories of the component Body Functions to be considered only in the presence of extra-articular manifestations of the disease.

Tables I-IV show the selected categories, the chapter of the ICF to which a category belongs, and the stages of the process at which the categories were selected.

The chapters with the highest number of categories selected in each component were the chapter Neuromusculoskeletal and movement-related functions from the component Body Functions, the chapter Structures relating to movement from the component Body Structures, the chapter Mobility from the component Activities and Participation, and the chapter Products and Technology from the component Environmental Factors. There was at least one category selected from all of the chapters within the component Environmental Factors.

78% of the ICF Core Set categories from the component Body Functions were selected during vote A or B and therefore at the level of the working groups. Similarly, 62% of the categories from the component Body Structures, 64% of the categories from the component Activities and Participation, and 45% of the categories from the component Environmental Factors were selected during vote A or B.

Discussion

A nominal group consensus process integrating evidence from preliminary studies and expert knowledge resulted in the development of a preliminary version of the Brief and the Comprehensive ICF Core Sets for patients with acute inflammatory arthritis.

The broad coverage of the components of Body Functions and Activities and Participation demonstrates the importance given to these components by all the professional groups. The selected categories generally represent problems that have been studied extensively in acute arthritis. The groups expressed the opinion that bodily impairments in

Table III. International Classification of Functioning, Disability and Health (ICF) – categories from the component Activities and Participation included in the Comprehensive and Brief ICF Core Sets for patients with acute arthritis. Votes A, B, and C indicate the stage of the process during which a category was selected (votes A and B were made by the working groups, while vote C was taken during the final plenary session).

ICF code	Category description	Vote	Brief Core Set
	Chapter: General tasks and demands		
	(2 categories selected out of 6 chapter categories)		
d230	Carrying out a daily routine	B	x
d240	Handling stress and other psychological demands	C	
	Chapter: Mobility		
	(11 categories selected out of 20 chapter categories)		
d410	Changing a basic body position	A	x
d415	Maintaining a body position	B	
d420	Transferring oneself	C	
d430	Lifting and carrying objects	A	
d435	Moving objects with the lower extremities	C	
d440	Fine hand use (picking up, grasping)	A	x
d445	Hand and arm use	A	x
d450	Walking	A	x
d460	Moving around in different locations	B	
d465	Moving around using equipment	B	
d470	Using transportation	B	
	Chapter: Self-care		
	(6 categories selected out of 9 chapter categories)		
d510	Washing oneself	A	x
d520	Caring for body parts	A	
d530	Toileting	A	x
d540	Dressing	A	x
d550	Eating	A	x
d560	Drinking	A	
	Chapter: Domestic life		
	(5 categories selected out of 11 chapter categories)		
d620	Acquisition of goods and services	B	
d630	Preparing meals	B	
d640	Doing housework	C	
d650	Caring for household objects	C	
d660	Assisting others	C	
	Chapter: Interpersonal interactions and relationships		
	(1 category selected out of 11 chapter categories)		
d770	Intimate relationships	C	
	Chapter: Major life areas		
	(2 categories selected out of 7 chapter categories)		
d840	Apprenticeship (work preparation)	C	
d845	Acquiring, keeping and terminating a job	C	x
d850	Remunerative employment	C	

rheumatic disease are a part of the initial disease presentation and not solely a consequence of the advancing disease process, and underlined the importance of both immediate symptom control and the early initiation of long-term multidisciplinary strategies to improve functioning, prevent disease progression, and preserve the quality of life. It was very interesting to observe that the groups adopted a patient-centred perspective from the very start of the consensus process.

Consistent with this approach, the experts included most of the functions, structures and activities of the musculoskeletal system (the main organ system involved), namely the chapters Neuromusculoskeletal and Movement-related functions (b7), Structures related to movement (s7), and Mobility (d4). Pain was included as a leading and most disabling impairment. Alongside pain, physical energy and sleep are the areas most frequently reported as problems by patients (18), and were included in both the Brief and Comprehensive Core Sets.

Impairment in respiration functions was discussed at length and finally included as an important and not infrequent systemic manifestation of disease. This is in line with studies reporting obstructive involvement of the lung to be as high as 23% in rheumatoid arthritis (19). Similarly, blood vessel functions were included after discussion of the underlying pathology. Inflammation in rheumatoid arthritis contributes to artherosclerosis and accounts for a raised cardiovascular morbidity (20).

It is not surprising that activities from the chapter Self Care were included almost unanimously in the first vote. In contrast, issues such as housework and preparing meals and acquiring, keeping and terminating a job, as well as many environmental factors were only included during the final round of voting, after the experts had agreed to take into account problems that were imminent and therefore part of the typical comprehensive intervention programme. Although most environmental factors are not amenable to alteration by therapy, an awareness of the problems commonly encountered by patients is important if strategies are to be developed that might alleviate the effects of poor social support or life circumstances.

Creating a cut-off point for the Brief Core Set was surprisingly straightforward. In addition, the experts agreed on a set of categories that characterized the extra-articular manifestations of the disease and could be used as an add-on for patients in whom such manifestations are present. Whether the Brief Core Set captures the most salient characteristics remains to be formally determined.

The ICF Core Set for acute arthritis is related to other, already existing ICF Core Sets comprising the acute (13) and early post-acute ICF Core Sets (12) for musculoskeletal conditions, which take a health service-oriented perspective, and the ICF Core Set for rheumatoid arthritis (14), which views arthritis as a chronic condition. As expected, the ICF Core Set for patients with musculoskeletal conditions, which was originally developed for non-specialised care in acute care hospitals, includes categories

Table IV. International Classification of Functioning, Disability and Health (ICF) – Categories from the component Environmental Factors included in the Comprehensive and Brief ICF Core Set for patients with acute arthritis. Vote A, B, C indicate the stage of the process at which a category was selected (votes A and B were made in the working groups, vote C was made in the final plenary session).

ICF code	Category description	Vote	Brief Core Set
	Chapter Products and technology		
	(7 categories selected out of 14 chapter categories)		
e110	Products or substances for personal consumption	A	x
e115	Products and technology for personal use in daily living	B	x
e120	Products and technology for personal indoor and outdoor mobility and transportation	A	x
e125	Products and technology for communication	C	
e135	Products and technology for employment	C	
e150	Design, construction and building products and technology of buildings for public use	A	
e155	Design, construction and building products and technology of buildings for private use	C	
	Chapter Natural environment and human-made changes to environment		
	(2 categories selected out of 13 chapter categories)		
e225	Climate	C	
e245	Time-related changes	C	
	Chapter Support and relationships		
	(4 categories selected out of 13 chapter categories)		
e310	Immediate family	B	
e320	Friends	C	
e340	Personal care providers and personal assistants	B	x
e355	Health professionals	B	x
	Chapter Attitudes		
	(4 categories selected out of 14 chapter categories)		
e410	Individual attitudes of immediate family members	B	x
e420	Individual attitudes of friends	C	
e440	Individual attitudes of personal care providers and personal assistants	C	
e450	Individual attitudes of health professionals	B	
	Chapter Services, systems and policies		
	(3 categories selected out of 20 chapter categories)		
e570	Social security, services, systems and policies	C	
e575	General social support services, systems and policies	C	
e580	Health services, systems and policies	C	x

relevant to critically ill patients, such as proprioception, respiratory muscle function, skin functions, and defecation and urination. However, it specifically reflects the needs of patients in intensive and intermediate care, and not those of patients with acute arthritis. As the acute ICF Core Set for musculoskeletal conditions must be applicable in the setting of the acute care hospital, it is much shorter and does not include a wide range of additional categories that are needed for the comprehensive care of patients with acute arthritis. As expected, there was also a considerable overlap between the early post-acute ICF Core Set for musculoskeletal conditions and the newly developed ICF Core Set for acute arthritis. Since this ICF Core Set for musculoskeletal conditions also covers the consequences of injuries, it contains some categories that are not relevant for patients for acute arthritis such as weight maintenance, urination and protective functions of the skin. Conversely, the ICF Core Set for acute arthritis includes more detail with regard to participation issues such as employment and intimate relationships, which have to be considered even in the acute care situation.

Another already developed ICF Core Set which is relevant to inflammatory arthritis is the Core Set for chronic rheumatoid arthritis (RA). Differences between the two core sets include sexual functions, which were not an issue in the ICF Core Set for acute arthritis, as well as the categories of community life and recreation and leisure. Such issues were not perceived as sufficiently problematic in the acute situation and hence were not included in the Core Set. In contrast, systemic manifestations of the disease that were not included in the chronic RA ICF Core Set, such as respiration or blood vessel functions, do appear in the acute ICF Core Set, reflecting the potentially life-threatening outcome of acute disease. Nevertheless, the similarities between the two ICF Core Sets reflect the continuum between acute and chronic joint disease. Therefore, it is important to recognize that the bodily impairments described in chronic rheumatic diseases begin early and that acute therapy must include early rehabilitation to address these longer-term disabilities at disease onset.

As possible limitations of the consensus process, it should be noted that only a small number of rheumatologists who take care of patients with acute arthritides and very few patients were involved. Since the comprehensive care of acute rheumatic diseases in specialized in-patient facilities constitutes an important part of rheumatologic patient care in Germany, we decided to mainly involve specialists from German hospitals in the initial process. This is also meaningful because of the multidisciplinary team approach that is an essential part of rheumatologic in-patient care in Germany. In addition, any consensus process requires excellent language skills and communication between participants; while it would have been possible to recruit physicians with sufficient language skills from all regions of the world, this would have been difficult for the nurses and other health professionals and could have led to a language bias against those health professionals. As a consequence of this approach, the generalizability of the results is not clear, and the ICF Core Set for acute arthritis will need to be tested and validated in the different WHO regions.

The choice of experts could also have introduced a selection bias in the results. It is therefore encouraging to note that, although the experts came

from different institutions and regions, the discussions were highly focused and the experts largely agreed on the typical features and characteristics of disease.

The ICF Core Set for patients with acute inflammatory arthritis offers a clinical framework to comprehensively assess patients, particularly in an interdisciplinary setting. It may be used for assessment and documentation, the assignment and planning of interventions, intervention management, and evaluation and is particularly useful for understanding the complex associations between disease consequences in rheumatic disease (2). Since it is based on the internationally understood and accepted ICF it can facilitate communication with regard to patient functioning and needs within and across clinical services (21). The Brief ICF Core Set could also serve as a standard for the reporting of clinical studies. This would facilitate the interpretation and comparison of results across studies, populations, settings and interventions (22).

The development of the ICF Core Set for acute arthritis also confirms the validity of the early post-acute ICF Core Set for musculoskeletal conditions. Many categories from the more general musculoskeletal ICF Core Set are also included in the condition- and situation-specific ICF Core Set for acute arthritis. At the same time, the ICF Core Set for chronic RA includes many categories that are relevant, but not relevant enough for the acute situation, which confirms the concept and validity of the ICF Core Set for chronic RA.

The ICF Core Set for acute arthritis complements the already existing ICF Core Sets. The problems and needs of rheumatology patients referred to and from acute care services can therefore easily be defined and communicated based on the ICF taxonomy. It is particularly useful to understand the complex associations between the disease and disability dimensions in rheumatic disease and the consequences of disease. The use of the ICF, and specifically the ICF Core Set for acute arthritis, may therefore contribute to the efficient patient- and need-oriented provision of services within the continuum of care from the acute care hospital to the community (22).

The ICF Core Set for patients with acute arthritis is currently undergoing testing and will be approved for German-speaking countries within a few years.

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