

The International Classification of Functioning, Disability and Health: a systematic review of observational studies

A Classificação Internacional de Funcionalidade, Incapacidade e Saúde: uma revisão sistemática de estudos observacionais

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ABSTRACT: *Objective:* To systematically review the use of the International Classification of Functioning, Disability and Health (ICF) in observational studies. *Methods:* This study is a systematic review of articles that use the ICF in observational studies. We took into account the observational design papers available in databases such as PubMed, Lilacs and SciELO, published in English and Portuguese from January 2001 to June 2011. We excluded those in which the samples did not comprise individuals, those about children and adolescents, and qualitative methodology articles. After reading the abstracts of 265 identified articles, 65 met the inclusion criteria. Of these, 18 were excluded. The STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) adapted Checklist, with 15 items needed for observational studies, was applied to the 47 remaining articles. Any paper that met 12 of these criteria was included in this systematic review. *Results:* 29 articles were reviewed. Regarding the ICF application methodology, the checklist was used in 31% of the articles, the core set in 31% and the ICF categories in 31%. In the remaining 7%, it was not possible to define the applied methodology. In most papers (41%), qualifiers were used in their original format. As far as the area of knowledge is concerned, most of the studies were related to Rheumatology (24%) and Orthopedics (21%). Regarding the study design, 83% of the articles used cross-sectional studies. *Conclusion:* Results indicate a wide scientific production related to ICF over the past 10 years. Different areas of knowledge are involved in the debate on the improvement of information on morbidity. However, there are only a few quantitative epidemiological studies involving the use of ICF. Future studies are needed to improve data related to functioning and disability. *Keywords:* International Classification of Functioning, Disability and Health. Chronic disease. Review literature as topic. Data collection. Evidence-based practice.

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RESUMO: *Objetivo:* Realizar uma revisão sistemática sobre o uso da Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF) em estudos observacionais. *Metodologia:* Trata-se de uma revisão sistemática de artigos que utilizaram a CIF em estudos observacionais. Foram incluídos artigos com desenho de estudo observacional disponíveis nas bases de dados do PubMed, Lilacs e SciELO, publicados em inglês e português no período de janeiro a junho de 2011. Foram excluídos aqueles em que a amostra não era composta por indivíduos, os que tratavam sobre crianças e adolescentes, e artigos com metodologia qualitativa. Após a leitura de 265 resumos identificados, 65 preencheram os critérios de inclusão. Desses, 18 foram excluídos. Nos 47 artigos incluídos foi aplicado o *checklist* adaptado do *Strengthening the Reporting of Observational Studies in Epidemiology* (STROBE) que contém 15 itens necessários para estudos observacionais. Artigos que preencheram 12 desses critérios foram incluídos na revisão sistemática. *Resultados:* Foram incluídos 29 artigos. Em relação à metodologia de aplicação da CIF, o *checklist* foi utilizado em 31%, o *core set* em 31%, as categorias da CIF em 31% e em 7% não foi possível definir a metodologia. Para o uso dos qualificadores, a aplicação na forma original foi a mais frequente (41%). Analisando os estudos por área de conhecimento, a maioria deles era referente às áreas de Reumatologia (24%) e Ortopedia (21%). Analisando o desenho de estudo, observou-se que 83% dos artigos eram estudos seccionais. *Conclusão:* Os resultados indicam um aumento da produção científica relacionada à CIF nos últimos 10 anos. Diferentes áreas de conhecimento estão envolvidas no debate sobre a melhoria das informações relacionadas à morbidade. No entanto, apenas um pequeno número de estudos epidemiológicos quantitativos utilizou a CIF. Futuros estudos são necessários para a melhoria dos dados relacionados à funcionalidade e incapacidade.

Palavras-chave: Classificação Internacional de Funcionalidade, Incapacidade e Saúde. Doença crônica. Literatura de revisão como assunto. Coleta de dados. Prática clínica baseada em evidências.

INTRODUCTION

The measurement of disability and functioning are topics of growing interest from the moment when chronic diseases have shown high prevalence and incidence, with the increase in life expectancy a characteristic phenomenon in modern societies. The inability, in particular, is a subjective and ambiguous category¹. As a result, the World Health Organization (WHO), for about 30 years, has been developing models for the understanding and classification of the phenomena of functioning, disability and deficiency².

In 1980, the WHO developed a classification to describe the consequences of adverse health conditions or diseases, called the International Classification of Impairments, Disabilities and Handicaps (ICIDH). The aim of this universal model was to provide a biopsychosocial representation of global health, including environmental, social, demographic and psychological contributions. The model consisted of three dimensions: impairment, described as loss or

alteration in the organs and systems and in the body structure; disability, characterized as any restriction or loss of ability in the performance of basic tasks; and handicap (disadvantage), which reflects the individual's adaptation to the environment resulting from the disability and impairment³.

The design of a model of linear causal relation (in which the damage to a body structure or function leads to disability, and this determines a disadvantage for the achievement of social roles) began to suffer criticism and questioning. Among these, there was the progression of a fixed sequence of events based on clinical onsets. Faced with the need of adaptation of the model, several partners from the WHO, together with governmental and nongovernmental organizations, including groups of people with special needs, engaged to review the ICIDH. As a result, in 2001 the WHO approved the International Classification of Functioning, Disability and Health (ICF)⁴.

The ICF is a classification system which describes the functioning and disability related to health conditions, reflecting a new approach which fails to focus only on the consequences of the disease, but also classifies health by biological, individual and social perspective in a multidirectional relation⁵.

In this context, the ICF is a tool created to provide a common language for describing the phenomena related to the health status and it is the most recent and embracing taxonomic model of functioning and disability within a universal and unified perspective. The new model offers a different perspective on impairment and disability, thus overcoming the prevailing biomedical model⁶.

The information is organized into two parts, with two components each. Part 1 (Functioning and Disability) consists of the domains of Body Functions (b) and Body Structures (s) and Activities & Participation (d). Part 2 (Contextual Factors) is formed by Environmental Factors (e) and by the Personal Factors (not subject to rating yet). The description of functionality involves the presence of a qualifier (which runs on a general scale of 0 to 4 where 0 means no impairment and 4 is a complete failure). The qualifiers show the magnitude of the disability, limitation, restriction, barriers or facilitators of health conditions⁷.

The ICF complements the indicators which traditionally have their focus on deaths or diseases, but they do not adequately capture the impact and consequences of the disease on individuals and on populations. The concepts presented in the classification introduce a new paradigm for thinking and working on impairments and disabilities, perceived not only as a consequence of the conditions of health/disease, but also determined by the context of the physical and social environment, by the different cultural perceptions and attitudes towards disability, by the availability of services and legislation⁸. This model of understanding functioning and disability is essential for the clinical diagnosis of the consequences of health conditions, power assignments as well as the evaluation of the results of the treatment⁹.

Gaidhane et al.¹⁰ report that the use of ICF quantitatively, as a systematic coding scheme of the information about functioning, disability and handicap, has several advantages,

such as: standardization of terminology; improvement of communication among health professionals; improvement of the data on the subject allowing comparisons among countries, disciplines and services throughout time; usage of the tool in order to identify the nature and magnitude of the multifactorial complex involved in the dimensions of disability and deficiency.

However, studies in Brazilian literature using the ICF quantitatively are scarce. Most of them deal with the concepts of classification and the importance of integration of the tool in the health field. In this sense, the present study aims at conducting a systematic review on the use of the ICF in observational studies. Furthermore, it is one of the objectives to describe how the classification has been used in the areas of knowledge and applied in clinical practice, the way on how to use the qualifiers and the main challenges for the implementation of the tool in clinical practice.

METHODOLOGY

A systematic review of the literature was conducted, considering, as an inclusion criteria, the publishing of articles with observational characteristics. Those whose sample did not consist on individuals, studies with children and adolescents, and articles on qualitative methodology (case report, focus group and methodology to link the ICF with measuring instruments) were excluded. Publications with the keyword "ICF", available on the data bases of PubMed (US National Library of Medicine), Latin American and Caribbean Literature Data on Health Sciences (LILACS) and Scientific Electronic Library Online (SciELO), published between January and June 2011, in English and Portuguese, were selected. The data were collected during the months of June and July 2011.

Of the 275 articles selected in the initial search, 65 of them were selected after the abstracts were read in full. Of these, 30 were excluded for not meeting the inclusion criteria. For the 35 selected articles, the adapted checklist for Strengthening the Reporting of Observational studies in Epidemiology (STROBE) was applied, an international initiative that encompasses recommendations for the improvement of the quality of the description of observational studies and which contains 15 items needed for these studies. The 29 articles that met 12 out of 15 of the criteria were included for analysis and discussion (Figure 1).

RESULTS

This systematic review included 29 studies that met the eligibility criteria. Cross-sectional studies were performed by 83% of the articles, the remaining ones (17%) conducted prospective cohort studies. Most of them used additional tools for the classification of functioning and disability. Table 1 summarizes the general characteristics of the reviewed studies.

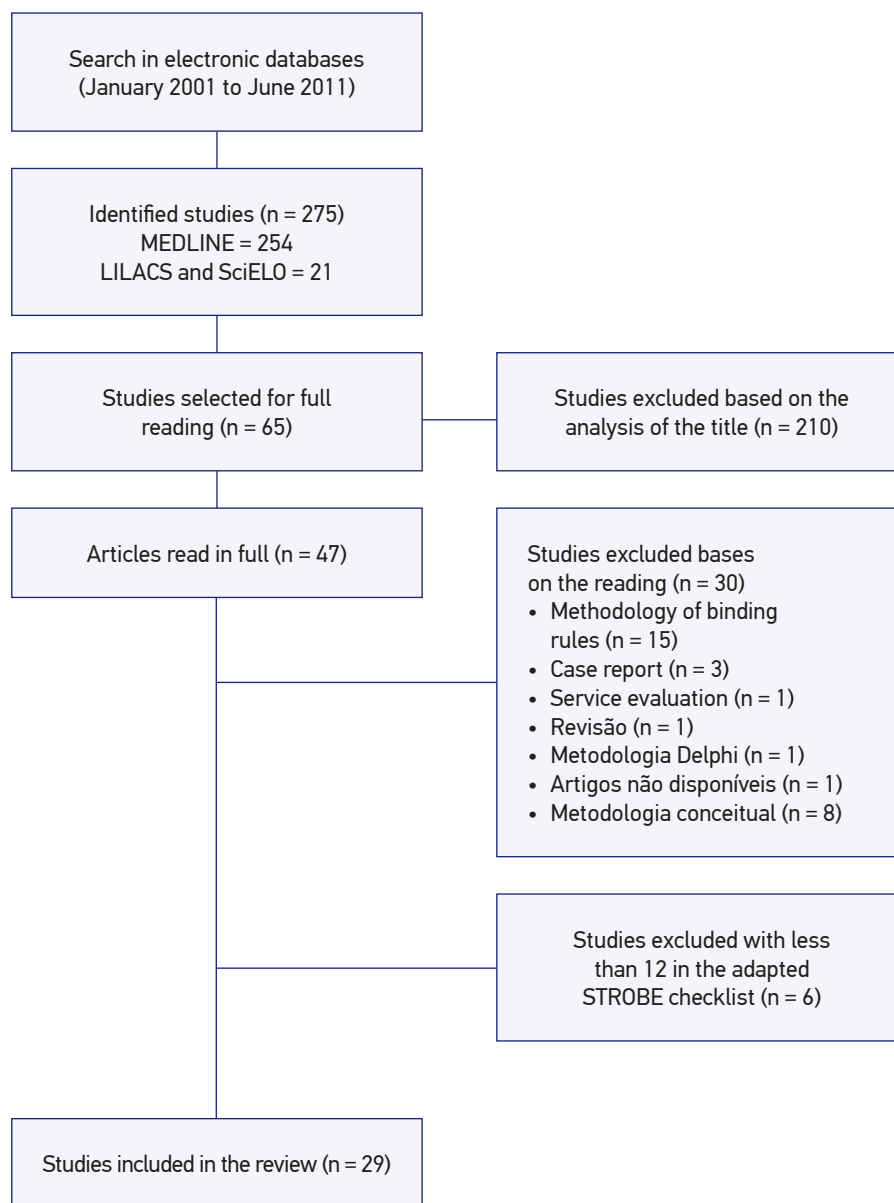


Figure 1. Criteria for identification of studies.

Regarding the method of the ICF use, 31% of the studies used the checklist, 31% the corsets and 31% the ICF categories. In the other (7%) it was not possible to define the used method (Figure 2). The qualifiers, in their original form, were used by 41% of the studies (Figure 3).

Analysing the studies by their knowledge areas, most of them related to the areas of Rheumatology (24%) and orthopedics (21%) (Figure 4).

Table 1. Description of the results of the selected studies (n = 29).

Author, year	Knowledge area	Design of the study	General goal	Population of the study	Sample size	ICF Methodology (Spare categories, checklist or core set)	Qualifiers (original or adapted)	Additional instruments
Almansa et al., 2011 ¹¹	Not definable	Cross-sectional	To assess whether the validity scales performance and capacity can be developed from the domains of activity and check list participation	Patients with 11 different chronic conditions	1092	Checklist	Original	YRSM, HDRS, MIDAS, EDSS, MIF
Peyrin-Biroulet et al., 2011 ¹²	Internal Medicine	Cross-sectional	To develop the first disability index for inflammatory bowel disease	Patients with inflammatory bowel disease	192	Checklist	Not definable	x
Gojlar et al., 2011 ¹³	Neurology	Cohort	To determine whether the ICF model is adequate for capturing the patterns of disability	Patients who had a stroke	197	Checklist	Original	MIF
Pollard et al., 2011 ¹⁴	Orthopedics	Cross-sectional	To examine the relationship between disability, limiting to activities and restriction to participation	Patients with osteoarthritis in situation prior to the hip and ankle arthroplasty	413	Categories	Adapted	x
Virúés-Ortega et al., 2011 ¹⁵	Geriatrics	Cross-sectional	To report the prevalence of disability (mild, moderate, severe and extreme)	Patients with more than 75 years of age	503	Not definable	Original	WHODAS II
Herrmann et al., 2011 ¹⁶	Neurology	Cross-sectional	To identify and quantify the differences in functionality	Patients with paraplegia and tetraplegia	1048	Not definable	Adapted	x
Gradinger et al., 2011 ¹⁷	Neurology	Cross-sectional	To identify the most common problems in patients with any degree of disorder of sleep	Patients with sleep disorders	99	Checklist	Adapted	x
Rogers et al., 2010 ¹⁸	Oncology	Cross-sectional	To develop a self-administered questionnaire in order to obtain the patient's vision over its content	Patients with head and neck cancer	364	Core set	Adapted	UW-QOL

Table 1. Continuation.

Author, year	Knowledge area	Design of the study	General goal	Population of the study	Sample size	ICF Methodology (Spare categories, checklist or core set)	Qualifiers (original or adapted)	Additional instruments
Rauch et al., 2009 ¹⁹	Rheumatology	Cross-sectional	To identify similarities and differences in functionality in patients with rheumatoid arthritis (RA) and ankylosing spondylitis (AS)	Patients with rheumatoid arthritis and ankylosing spondylitis	230	Core set	Original	x
Taylor et al., 2010 ²⁰	Rheumatology	Cross-sectional	To determine the categories of the checklist and the core set for RA and AS in patients with frequent psoriatic arthritis	Patients with psoriatic arthritis	94	Checklist	Original	WHODAS II, PAR-PRO, SF-36, Psa-QOL, HAQ-DI
Cieza et al., 2009 ²¹	Orthopedics	Cross-sectional	To explore the possibility of building clinical measures of functionality by integrating information from the categories of core set for osteoarthritis	Patients with Osteoarthritis	437	Core set	Original	X
Tsutsui et al., 2008 ²²	Nephrology	Cross-sectional	Identify the most common problems in Japanese patients on hemodialysis	Patients on hemodialysis	136	Checklist and categories	Not definable	x
Tschiesner et al., 2009 ²³	Oncology	Cross-sectional	To assess the level of functionality in patients with head and neck cancer through the ICF	Patients with head and neck cancer	145	Checklist and categories	Original	EORTC
Hilfiker et al., 2009 ²⁴	Orthopedics	Cohort	To evaluate the inter-rater (two raters) agreement using the core set for low back pain	Patients with low back pain	61	Core set	Adapted	SF-36, SCQ
Rastogi et al., 2008 ²⁵	Orthopedics	Cohort	To quantify the level of importance on the areas of functionality	Preoperative and postoperative patients	54	Categories	Adapted	NPRS, KOOS

Table 1. Continuation.

Author, year	Knowledge area	Design of the study	General goal	Population of the study	Sample size	ICF Methodology (Spare categories, checklist or core set)	Qualifiers (original or adapted)	Additional instruments
Bautz-Holter et al., 2008 ²⁶	Orthopedics	Cross-sectional	To evaluate the Norwegian version of the core set for low back pain and to investigate the feasibility of application in clinical practice	Patients with low back pain	118	Core set	Original	SF-36, SCQ, ODI
Xie et al., 2008 ²⁷	Orthopedics	Cross-sectional	To validate the abbreviated core set for osteoarthritis	Patients with Osteoarthritis	122	Core set	Not definable	SF-36, SCQ
Uhlig et al. ²⁸	Rheumatology	Cohort	To investigate the responsiveness of the rheumatoid arthritis core set in clinical practice	Patients with rheumatoid arthritis	46	Core set	Adapted	MHAQ, SF-36
Grill e Stucki, 2008 ²⁹	Not definable	Cross-sectional	To examine whether clinical assessments tomade with the ICF can be integrated into parametric scales	Patients with musculoskeletal conditions	234	Core set	Adapted	X
Gaidhane et al., 2008 ³⁰	Infectology	Cross-sectional	To verify the perception of self-care in patients with HIV/AIDS	Patients with HIV/AIDS	194	Cathegories	Original	X
Jonsson et al., 2008 ³¹	Neurology	Cross-sectional	To describe, through the use of environmental factors of the ICF, the social groups that participate in the life of adults with cerebral palsy	Patients with cerebral palsy	16	Cathegories	Original	X
Farin et al., 2007 ³²	Not definable	Cross-sectional	To develop a self-guided questionnaire for the categories of mobility and self-care based on ICF	Patients with various conditions	1019	Cathegories	Not definable	X
Verhoef et al., 1007 ³³	Rheumatology	Cohort	To investigate whether the use of an instrument based on ICF improves clinical outcomes and patient satisfaction with the multidisciplinary team	Patients with rheumatoid arthritis	165	Cathegories	Not definable	MACTAR, RaQoI, DAS28

Table 1. Continuation.

Author, year	Knowledge area	Design of the study	General goal	Population of the study	Sample size	ICF Methodology (Spare categories, checklist or core set)	Qualifiers (original or adapted)	Additional instruments
Grill et al., 2007 ³⁴	Not definable	Cross-sectional	To observe an agreement in description and classification using the ICF	Patients with various conditions	25	Categories	Adapted	X
Echteld et al., 2006 ³⁵	Rheumatology	Cross-sectional	To identify the most common problems in patients with ankylosing spondylitis	Patients with ankylosing spondylitis	111	Checklist	Original	SACQ, BASFI
Cieza et al., 2006 ³⁶	Not definable	Cross-sectional	To propose a method to select ICF categories when a large amount of data must be handled and to identify categories for a generic core set	Not definable	1.039	Checklist	Adapted	SF-36
Zochling et al., 2006 ³⁷	Rheumatology	Cross-sectional	To identify the most common problems in patients with acute inflammatory arthritis	Patients with acute inflammatory arthritis	130	Categories	Adapted	X
Riberto et al. ³⁸	Rheumatology	Cross-sectional	Description of the results of the application of core sets for chronic widespread pain	Patients with fibromyalgia	29	Core set	Original	X
Buchalla e Cavalheiro ³⁹	Infectology	Cross-sectional	To propose a preliminary version of the core set for HIV	Patients with HIV/AIDS	42	Categories	Not definable	X

YRSM: Young Rating Scale of Mania; HDRS: Hamilton Depression Rating Scale; MIDAS: Migraine Disability Assessment Questionnaire; EDSS: Expanded Disability Status Scale; MIF: Medida de Independência Funcional; WHODAS II: WHO Disability Assessment Schedule II; SF-36: Medical Outcomes Study Short-Form 36; PsA-QOL: PsA-Specific QOL Instrument; HAQ-DI: Health Assessment Questionnaire Damage Index; SQC: Social Communication Questionnaire; ODI: Oswestry Disability Index; MHAQ: Modified Health Assessment Questionnaire; BASFI: Bath Ankylosing Spondylitis Functional Index; SACQ: Self-Administered Comorbidity Questionnaire; UW-QOL: University of Washington Quality of Life; NPRS: Numeric Pain Rating Scale; KOOS: Knee Injury and Osteoarthritis Outcome Scale; MACTAR: McMaster Toronto Arthritis Patient Preference Disability Questionnaire; RaQol: Rheumatoid Arthritis Quality of life questionnaire; DAS28: Disease Activity Score.

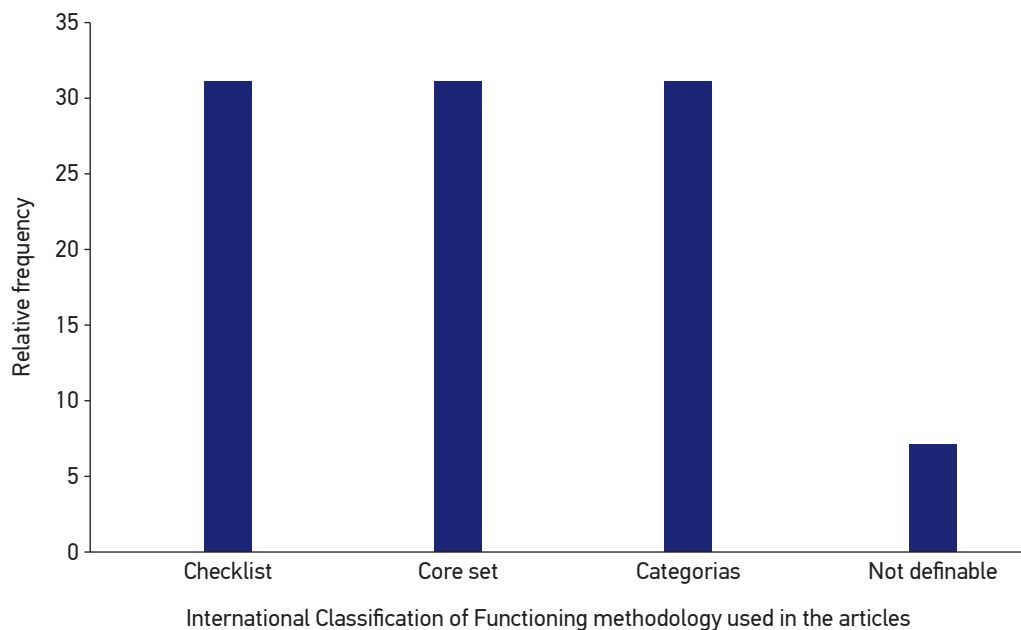
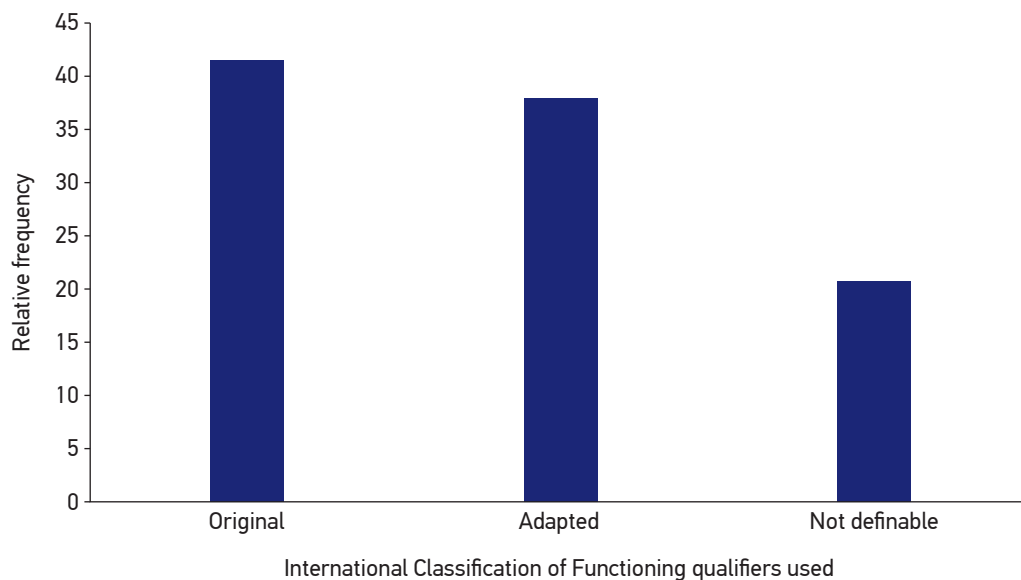


Figure 2. Methodology used in the articles of the International Classification of Functioning included in the systematic review (n = 29).



Note: Qualifier was considered adapted when the study did not use it in the original form. The original scale ranges from 0 to 4, and in adaptations, the original scale was categorized dichotomously. Example: Ranked disability as present or absent.

Figure 3. Qualifiers frequency used in the articles of the International Classification of Functioning included in the systematic review (n = 29).

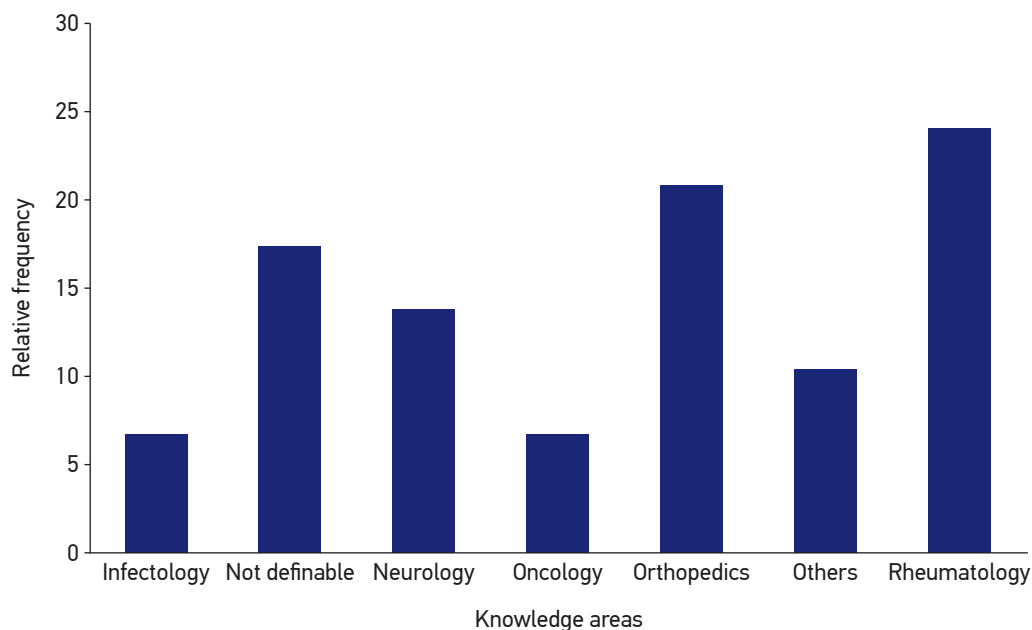


Figure 4. Knowledge areas of the articles of the International Classification of Functioning (n = 29).

DISCUSSION

The ICF appears on the world scenery of rehabilitation as a promising, with high potential of applicability and compliance, tool¹⁹. Almansa et al.¹¹ point out that a major goal of the classification is the systematic recording of information regardless of the method used in order to obtain or access these information. They also evidence that the classification should not be restricted only to the qualitative and/or conceptual use, but it should also be used as a statistical and epidemiological tool. The aim of this study was to conduct a review of the studies which used the ICF quantitatively.

Some years after the publication of the ICF, the WHO has identified that the classification (in their original format, with approximately 1,500 categories) was impractical for everyday use. Thus, it was suggested the development short lists of relevant concepts to specific health conditions and chronic situation. There are two versions of core sets: comprehensive (recommended for research purposes) and abbreviated (for use in clinical practice). Models for stroke, chronic obstructive pulmonary disease, obesity, coronary heart disease, orthopedic conditions, among others have been published and some are still in development³⁸. However, the use of core sets is not fully accepted by the scientific community due to the possibility of returning to the biomedical model (focus on the disease and not the functionality).

Our results demonstrate that a large number of articles used the core set in their methodology (31%), both in the comprehensive and short versions. It was also

observed that no author used the ICF in its full version and that the articles which used spare ICF categories, mostly, used these categories for assembling questionnaires and clinical assessment scales.

There are some difficulties in implementing the ICF in clinical practice, since this classification does not indicate the instruments needed for the assessment of disability and functionality. The proper use of the instrument depends on the user and the purpose, and there will always be many measurement options, although refinements and changes in classification are necessary. In this sense, Grill et al.³² emphasize that the ICF has no psychometric characteristics with defined objective, thus compromising its properties of reliability and validity. It is also noteworthy that the basis for the ICF application, both in clinical practice and in the research field, takes place through the use of practical tools such as core sets.

In a recent review of the implementation and operationalization of ICF since its publication, it was noted that there is an ongoing scientific activity surrounding the spread of classification through theoretical publications in the fields of education, social security and labor. However, only 26% of publications are related to the clinical practice and/or rehabilitation. The authors conclude that the greater the availability of tools guided by the ICF, the better the data on population health within the information systems³⁹. However, such review was qualitative and its results should be interpreted with caution. The results demonstrated the predominance of cross-sectional studies (83%). This, points to the difficulty of introducing the ICF in longitudinal epidemiological studies.

In another systematic review, Jelsma⁴⁰ concluded that the ICF, over the past few years, made a big impact on how data on deficiency and disability are conceptualized, collected and processed. He stressed that the classification has been used in various disciplines, health conditions, sectors and settings, and that the use of the ICF in developing countries should be encouraged. The results show a small scientific production using the ICF in Latin America. This can be explained by the fact that the number of studies identified on the basis of Lilacs was much lower than the number identified in the PubMed database.

Another limiting issue is that the fact qualifiers require standardization and that they present some difficulty in their psychometric characteristics. Goljar et al.¹³ highlight that the use of the ICF qualifiers is not yet fully operationalized, although many attempts have been made towards the validation of the use of operational scales. However, such difficulties and obstacles will only be solved if there is adherence by professionals and a practical use of the ICF. Our results indicate that about 35% of the studies used the qualifiers in an adapted way, which goes against the difficulties found by many authors. These authors usually adapt the qualifiers for dichotomous response option, thus providing a prevalence measure of the disability and not an analysis of the phenomenon of gravity. This adaptation is not consistent with the original model of the ICF.

The objective of this systematic review was to demonstrate how the ICF has been used in observational studies, however, a limitation of this study is the fact that the quality of the articles was not analyzed. In an attempt to reduce this problem, an adapted version of the STROBE was used. The checklist of the initiative is not an evaluative document, however, the choice of using it was an attempt to elect the authors with better methodological quality. The adapted document consisted of 15 questions and articles that reached 12 positive responses were included. The cutoff point chosen was subjective.

The results found in this review may be a starting point for future discussions involving the quantitative aspects of the ICF. Questions about the methodology involving or not the use of core sets, psychometric properties of the qualifiers and areas of knowledge yet with little participation can be explored in future studies.

CONCLUSION

The results indicate a wide scientific production related to the International Classification of Functioning, Disability and Health over the past 10 years. Several knowledge areas and sectors of the health field are involved in the debate on the improvement of information on morbidity. However, the quantitative epidemiological studies involving the use of ICF in clinical practice are few, if compared to the qualitative studies. Future studies are needed in order to improve the secondary data related to functioning and disability.

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