ORIGINAL ARTICLE

The ICF-CY for children and adolescents with osteogenesis imperfecta: the perspective of specialists

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ABSTRACT

Objective: From the perspective of specialists in Osteogenesis Imperfecta (OI), to identify the most relevant categories of the International Classification of Functioning, Disability, and Health: children and youth version (ICF-CY) to patients. **Methods:** Three-stage surveys were sent by email to five OI specialists using the modified Delphi method. From a list of second-level ICF-CY categories, the participants chose the most relevant categories to assess the functioning of children and adolescents with OI. At the end of the third stage, the categories considered relevant by at least 80% of the responders were selected. **Results:** Categorizations of all ICF-CY components were agreed upon. Activities, Participation, and Environmental Factors were the categories with the most components. **Conclusion:** A list of ICF-CY categories relevant to OI could be created from the perspective of specialists. This is an important step to highlight what to assess in children and adolescents with OI.

Keywords: International Classification of Functioning, Disability and Health, Osteogenesis Imperfecta, Consensus

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INTRODUCTION

In Osteogenesis Imperfecta (OI) the quantitative and qualitative alterations of the collagen type I determine the main clinical manifestations of the disease: osteopenia, bone fragility, and progressive skeletal deformities.[1]

Impairments concerning problems in the functions and structures of the body are the primary consequences of OI. However, when interacting with the physical and social environment, children and adolescents with this disease experience other disabilities such as restrictions in their activities of daily living and limitations in performing their expected social roles.[2] Given the diversity and complexity of the OI disabilities, the functioning of children and adolescents afflicted by it must be considered from a comprehensive perspective associated not only with the health condition, but also with environmental and personal factors.[3]

The International Classification of Functioning, Disability, and Health: children and youth version (ICF-CY)[4] proposes an integrative model that provides a multidimensional, ecological, and interdisciplinary understanding of the functioning of children and adolescents considering the biological, social, and individual perspectives.[3] The classification is organized by two components: 1- *Body Functions* (prefix *b*) *and Body Structures* (prefix *s*), and 2- *Activities and Participation* (prefix *d*)*, and t*he contextual factors that may impact the functioning of the child are represented by 2 factors: 1- *Environmental factors* (Prefix *e*), and 2- *Personal factors.* Each component with the exception of Personal Factors consists of several domains (chapters), and within each domain are the categories that are the units of classification. They are represented by alphanumeric codes in that the letters (*b,s,d,e*) represent the components and the numbers represent the chapter/domain (first digit) followed by the second level (2 digits), third and fourth levels (1 digit each).[4] In the ICF-CY there are 380 second-level categories organized by their components in the following way: 118 categories of Body Functions, 56 categories of Body Structures, 132 categories of Activities and Participation, and 74 categories of Environmental Factors.

The ICF-CY provides a common language for the functionality in which the functional profile of children with a health condition can be traced. This profile is important in defining what must be assessed.[5] In a disease with various repercussions and multidisciplinary intervention as the OI, a comprehensive approach to ICF-CY can help to define which aspects of functionality and contextual factors must be considered in the evaluation of children and adolescents.

The large number of categories of ICF-CY has been a complicating factor for its practical use. To facilitate its applicability, *Core sets* have been developed.[6] *Core sets* are a set of categories that represent the functional areas most relevant to a given health condition chosen from a methodology based on evidence supported by the World Health Organization.[6] This methodology and the selected categories of ICF-CY for OI were based on the perspectives of researchers, children and adolescents with OI, and specialists. This article describes the categories chosen based on the opinion of specialists who work with OI.

OBJECTIVE

The objective of this study was to identify which categories of the ICF-CY are the most relevant for the assessment of children and adolescents with OI, considering the perspective of specialists.

METHOD

One possible approach to developing a list of categories to describe functioning in a given health condition is the Delphi Method.[7-10]

Through the application of questionnaires, the Delphi aimed to reach a consensus in a group of specialists on a specific matter where a prior agreement did not exist.[7] The method is characterized by four things: 1- anonymity between specialists, 2- interaction with *feedback* by providing a panorama on the individual and group positioning in relation to each item of the questionnaire in the previous stage, 3- statistical analysis of the answers, and 4- use of specialists in the subject that is being studied.[8,9]

For the recruitment of the participants, letters of invitation were sent to twelve professionals from different specialties who worked in OI Reference Centers in Brazil. The letter stated the objectives of the study, the methodology that would be used, and the inclusion criteria for the study, namely: experience of at least two years in pediatrics and in Osteogenesis Imperfecta.

Five specialists agreed to participate in the study and they initially received a demographic questionnaire, material with information on the ICF, and their identification code. The specialists had no knowledge of who was participating in the study.

The *Google Drive* tool was used to prepare the questionnaires*.* Each questionnaire was organized in forms referring to the components *Body Functions and Body Structures, Activities and Participation,* and *Environmental Factors*. There were three stages of questionnaires sent by e-mail to the participants.

The deadline for submitting answers to each questionnaire was two weeks, and reminders were sent one week and again two days before the closing date for responding. In each stage, detailed explanations were provided about filling in the questionnaires. The process began in the second half of 2014 and lasted about 12 weeks.

First stage of the questionnaire

A structured questionnaire was sent with 323 categories from the second level of the ICF-CY. The qualifiers 9 ("not specified") were excluded. In this way the first questionnaire was made up of 4 forms with 97 *Body Functions* categories, 48 *Body Structures* categories, 109 *Activities and Participation* categories, and 69 *Environmental Factors* categories*.*

The use of a closed questionnaire instead of an open questionnaire in the first stage is called modified Delphi. This methodological alteration is recommended in situations in which information is previously collected from the literature before drafting the first questionnaire.[7]

Second-level ICF-CY categories were chosen to compose the questionnaires because they include the attributes of higher--level categories.[4] Participants were asked at this stage to choose categories that were relevant to the assessment of children and adolescents with OI.

Second stage of the questionnaire

The second-stage questionnaire was developed considering 3 things: 1- the categories selected in the previous stage by at least one specialist; 2- *feedback* on the individual and group choices in relation to each category in the first questionnaire; 3- the percentage of participants who considered that category as relevant in questionnaire 1. The participants were identified through numeric codes. At this phase they were asked

whether a specific category was one of the ***most*** relevant for the assessment of children and adolescents with OI. This stage had the same participants as the previous one.

Third stage of the questionnaire

The third-stage questionnaire included the same categories as stage 2, so each one of them had the same opportunity to receive the highest level of consensus at the end of the third questionnaire. In this stage the participants were asked to choose the categories ***most*** relevant considering the individual and group opinions in the previous stage. They also received a *feedback* on the individual and group choices and the percentage of choice for each category in questionnaire 2. Again, this stage had the same participants as the previous.

Descriptive analyses were used to calculate the response rates and the percentage of choice for each category.

At the end of the third stage, those categories with a consensus level of 80% or more were chosen as the responses of the study. This level of consensus was stipulated before the beginning of the study and was chosen because it was believed that a higher cutoff point (100%) would generate too few categories, while lower cutting points would generate too many.

This research was approved by the Ethics in Human Research Committee of the Fernandes Figueira National Institute of Women, Children, and Adolescent Health (IFF/Fiocruz) through the report No. CAAE 30619114.3.0000.5269 and each participant signed the Free and Informed Consent Term.

RESULTS

Participants

The study had the participation of 2 physicians, 2 physiotherapists, and 1 social worker. The mean age of participants was 45.8 years. The mean time of practice in pediatrics and OI were respectively 22 years and 9.2 years. The response rate from all three stages of questionnaires was 100%.

First stage of the questionnaire

Of the 323 ICF-CY second level categories in the first stage, the participants chose 257 categories distributed throughout all components.

Eighty-two categories reached the consensus of 80% or more in the first stage (Table 1). The domains that achieved the highest consensus were b7 (Neuromusculoskeletal and Movement-related Functions), s7 (Structures related to movement), d4 (Mobility) and e1 (Products and Technology) (Table 2).

Second stage of the questionnaire

In the second stage, 93 categories reached the consensus of 80% or more. The quantity of categories with the consensus stipulated has increased for all components, particularly *Activities and participation* and *Environmental factors* (Table 1). The domains that have achieved the highest consensus were the same as those cited in the previous stage with addition of d5 (Personal Care) (Table 2).

Third stage of the questionnaire

The consensus remained stable considering the total number of categories with consensus ≥ 80%. As for the components, the consensus decreased for the *Body Functions* component and increased mainly in the *Environmental Factors* component (Table 1). For the former, the domain that presented the greatest reduction of consensus was b1 (Mental functions). For *Environmental Factors* the domains that had the greatest increase in consensus in the third stage were e4 (Attitudes) and e5 (Services, systems, and policies) (Table 2).

Description of categories with 80% or more consensus in the third stage

In the *Body Functions* component, the categories that reached 80% consensus or more belong mainly to areas b4 (Functions of the cardiovascular, hematological, immunological, and respiratory systems) and b7 (Neuromusculoskeletal and movement-related functions) (Table 2 and Table 3).

For the *Body Structures* component, the majority of categories that reached 80% consensus or more (7 categories) belong to the area s7 (Structures related to movement) (Tables 2 and 3).

The areas most represented by the categories that reached consensus on the component *Activities and Participation* were d4 (Mobility) and d5 (Personal care) (Table 2 and Table 3).

In relation to *Environmental Factors,* all areas presented categories with the stipulated consensus, the main ones being e1 (Products and technology) and e5 (Services, systems and policies) (Table 2 and Table 3).

Analyzing the 93 categories that reached the expected consensus at the end of the third stage, it was verified that 37 reached a 100% consensus from the first stage of the study, especially for characteristics such as functions (b7) and musculoskeletal structures (s7) and Mobility (d4) (Table 3). In relation to the categories that initially did not show a consensus, it was seen that they represented environmental factors such as Attitudes (e4) and Services, Systems, and Policies (e5) (Table 3).

DISCUSSION

Taking into account the methodology recommended by the World Health Organization for the preparation of *Core Sets,*[6] the Delphi method has been used to verify the view of specialist on ICF categories that are relevant to specific health conditions.[5,11] When compared to only one stage of the questionnaire, the Delphi allows a more comprehensive approach to the researched topic, plus the flexibility to change opinion.[7] In the present study, through the three stages of questionnaires, a high level of consensus was achieved on which ICF-CY categories are the most relevant for the assessment of the functioning of children and adolescents with OI.

In the view of specialists, children and adolescents with OI should have aspects of all the functioning components evaluated. From the ICF-CY categories that have been agreed upon, it was verified that not only the areas primarily affected by the disease (bone structure, growth) were deemed im-

Table 1. The consensus process from the first to the third stages

	Body Functions	Body Structures	Activities and Participation	Environmental Factors	Total
Total number of identified categories (n)	76	35	95	51	257
Questionnaire 1 ICF-CY categories with ≥ 80% consensus (n)	28	9	27	18	82
Questionnaire 2 categories with ≥ 80% consensus (n)	29	10	31	23	93
Questionnaire 3 categories with ≥ 80% consensus (n)	22	10	32	29	93

Table 2. The consensus process from the first to the third stages by domains

ICF-CY domains	Number of categories with 80% or more consensus		
	Q1	Q2	Q3
b1 Mental functions	1	4	0
b2 Sensory functions and pain	5	4	3
b3 Voice and speech functions	0	0	0
b4 Functions of the cardiovascular, hematological, immunological, and respiratory systems	5	6	5
b5 Functions of the digestive, metabolic, and endocrine systems	3	2	2
b6 Genitourinary and reproductive functions	2	1	2
b7 Neuromusculoskeletal and movement-related functions	12	12	10
b8 Functions of the skin and related structures	0	0	0
s1 Structures of the nervous system	0	0	0
s2 The eye, ear, and related structures	0	1	1
s3 Structures involved in voice and speech	0	0	0
s4 Structures of the cardiovascular, respiratory, and immune systems	2	2	2
s5 Structures related to the digestive, metabolic, and endocrine systems	0	0	0
s6 Structures related to the genitourinary and reproductive systems	0	0	0
s7 Structures related to movement	7	7	7
s8 Skin and related structures	0	0	0
d1 Learning and applying knowledge	1	1	1
d2 General tasks and demands	2	3	4
d3 Communication	0	0	0
d4 Mobility	13	13	13
d5 Personal Care	6	8	8
d6 Domestic life	0	0	0
d7 Interpersonal interactions and relationships	0	0	0
d8 Major life areas	2	3	3
d9 Community, social, and civic life	3	3	3
e1 Products and Technology	7	8	8
e2 Natural environment and human-made changes to the environment	0	1	1
e3 Support and relationships	6	7	7
e4 Attitudes	0	1	4
e5 Services, systems, and policies	5	6	9
Total	82	93	93

portant, but also the associated characteristics (hearing, respiratory function, pain), their impacts in activities and participation, and the contextual factors that interact with these aspects.

For the *Body Functions* and *Body Structures* components, most of the categories represented functions and structures of movement and of the cardiorespiratory system. These findings reflect the main and associated characteristics of the disease already described in the literature: the affliction of the musculoskeletal functions and structures and of the cardiopulmonary function.[2,12,13]

Special emphasis was given by specialists to the *Activities and Participation* and *Environmental Factors* components. In relation to the first component, the participants recognized especially the importance of mobility and self-care, domains essentially related to activity.[14] These findings are in line with studies that indicate the affliction of these domains in children with OI.[2,12] Although the importance of interpersonal relations (d7) has been reported by children and adolescents with the disease,[15,16] specialists did not consider this domain as relevant. The fact of the traditional methods of assessment focusing on the carrying out of activities to the detriment of social involvement may be an explanation for this finding.[17] In particular, the domain "interpersonal interactions and relationships" is the least appreciated in the instruments of evaluation of participation.[14]

Regarding the Environmental Factors, all areas of this component were chosen showing the importance given by specialists to the children's interaction with the context. The aspects of the physical environment considered most relevant were related to "Products and technologies" adapted to improve functioning and "Services, systems, and policies." In agreement with these results, a review study on the environmental factors that influence the participation of children and adolescents with disabilities pointed to physical environment, transportation, policies, and the lack of support by the team providing services as the major barriers.[18]

The ICF-CY categories that obtained a high consensus since the first questionnaire indicated that the disease, despite clinical heterogeneity, has very characteristic incapacities: deficiencies in the musculoskeletal functions and structures and impact on mobility.

The fact that some aspects of Attitudes (e4) and Services, systems, and policies (e5) only reach a consensus at the end of the study indicates that these characteristics are not the first considered as relevant by professionals. This finding can be justified by the professional training of most specialists participating in the study.

The generalization of the results of this study is limited, because in spite of the effort to recruit professionals from various specialties and from different treatment centers, the majority of the participants belonged only to one center and were mainly either physicians or physical therapists. Due to this fact, the selection of categories, as well as the importance given to some of them, perceptible through the level of consensus, may have been over or underestimated. We believe, however, that this limitation does not invalidate the present study because there is an agreement of its findings with those of international studies on the functioning of children and adolescents with OI.

CONCLUSION

Through the opinion of a group of specialists, a comprehensive profile of functioning in OI was obtained, especially for functional areas and contextual factors. From the ICF-CY structure, it was possible to point

Table 3. ICF-CY categories considered relevant by more than 80% of the participants at the end of the third stage, and the process of consensus from the first to the third stages

Categoria da CIF-CJ	Nível de consenso		
	Q1	Q2	Q3
Body functions			
b230 Hearing functions	80%	80%	100%
b235 Vestibular functions	80%	100%	80%
b280 Pain	100%	80%	100%
b410 Functions of the heart	60%	80%	80%
b440 Respiration functions	80%	100%	100%
b445 Respiratory muscle functions	80%	100%	100%
b455 Exercise tolerance functions	80%	100%	100%
b460 Sensations associated with cardiovascular and respiratory functions	80%	100%	100%
b530 Weight maintenance functions	100%	100%	100%
b560 Growth maintenance functions	100%	100%	100%
b650 Menstruation functions	100%	100%	100%
b660 Procreation functions	80%	60%	80%
b710 Mobility of joint functions	100%	100%	100%
b715 Stability of joint functions	100%	100%	100%
b720 Mobility of bone functions	100%	100%	100%
b730 Muscle power functions	100%	100%	100%
b735 Muscle tone functions	100%	100%	100%
b740 Muscle endurance functions	100%	100%	100%
b760 Control of voluntary movement functions	80%	80%	100%
b761 Spontaneous movements	80%	80%	80%
b770 Gait pattern functions	100%	100%	100%
b780 Sensations related to muscles and movement functions	80%	100%	100%
Body structures			
s260 Structure of inner ear	60%	80%	80%
s410 Structure of cardiovascular system	80%	100%	100%
s430 Structure of respiratory system	80%	100%	100%
s710 Structure of head and neck region	100%	100%	100%
s720 Structure of shoulder region	100%	100%	100%
s730 Structure of upper extremity	100%	100%	100%
s740 Structure of pelvic region	100%	100%	100%
s750 Structure of the lower extremity	100%	100%	100%
s760 Structure of trunk	100%	100%	100%
s770 Additional musculoskeletal structures related to movement	100%	100%	100%
Activities and Participation			
d115 Listening	80%	80%	80%
d210 Undertaking a single task	60%	80%	80%
d220 Undertaking multiple tasks	60%	60%	80%
d230 Carrying out daily routines	100%	100%	100%
d240 Handling stress and other psychological demands	80%	80%	100%
d410 Changing basic body position	100%	100%	100%
d415 Maintaining a body position	100%	100%	100%
d420 Transferring oneself	100%	100%	100%
d430 Lifting and carrying objects	100%	100%	100%
d435 Moving objects with lower extremities	100%	100%	100%
d440 Fine hand use	100%	100%	100%
d445 Hand and arm use	100%	100%	100%
d446 Fine foot use	100%	100%	100%

Continued Table 3

d450 Walking	100%	100%	100%
d455 Moving around	60%	80%	80%
d460 Moving around in different locations	100%	100%	100%
d465 Moving around using equipment	100%	100%	100%
d470 Using Transportation	100%	100%	100%
d510 Washing oneself	100%	100%	100%
d520 Caring for body parts	100%	100%	100%
d530 Toileting	80%	100%	100%
d540 Dressing	100%	100%	100%
d550 Eating	60%	100%	100%
d560 Drinking	60%	100%	100%
d570 Looking after one's health	80%	100%	100%
d571 Looking after one's safety	80%	100%	100%
d820 School Education	80%	100%	100%
d825 Vocational Training	60%	80%	80%
d835 School life and related activities	80%	100%	80%
d920 Recreation and leisure	100%	100%	100%
d940 Human Rights	80%	100%	100%
d950 Political life and citizenship	80%	100%	100%
Environmental Factors			
e115 Products and technology for personal use in daily living	100%	100%	100%
e120 Products and technology for personal indoor and outdoor mobility and transportation	100%	100%	100%
e130 Products and technology for education	80%	100%	100%
e135 Products and technology for employment	80%	80%	80%
e140 Products and technology for culture, recreation, and sport	60%	100%	100%
e150 Design, construction and building products and technology of buildings for public use	100%	100%	100%
e155 Design, construction, and building products, and technology of buildings for private use	80%	100%	100%
e165 Assets	80%	100%	100%
e215 Population	60%	80%	80%
e310 Immediate family	80%	100%	100%
e315 Extended family	80%	100%	100%
e320 Friends	80%	100%	100%
e325 Acquaintances, peers, colleagues, neighbors, and community members	60%	100%	100%
e330 Persons in positions of authority	80%	100%	100%
e340 Personal care providers and personal assistants	80%	100%	100%
e355 Health professionals	80%	100%	100%
e410 Individual attitudes of immediate family members	60%	60%	80%
e420 Individual attitudes of friends	60%	60%	80%
e440 Individual attitudes of personal care providers and personal assistants	60%	60%	80%
e450 Individual attitudes of health professionals	60%	80%	80%
e515 Architecture and construction services, systems, and policies	80%	100%	100%
e520 Open space planning services, systems, and policies	80%	80%	100%
e530 Utilities services, systems, and policies	40%	60%	80%
e535 Communication services, systems, and policies	60%	60%	80%
e540 Transportation services, systems, and policies	80%	100%	100%
e555 Associations and organizational services, systems, and policies	80%	100%	100%
e570 Social security services, systems, and policies	80%	100%	100%
e580 Health services, systems, and policies	60%	80%	80%
e585 Education and training services, systems, and policies	60%	80%	80%

out important aspects to be considered in the functioning of children and adolescents with OI. The results of this study have the potential to facilitate the use of the ICF-CY in this population.

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