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Toward the Development of the International Classification of Functioning Core Sets for Children With Cerebral Palsy: A Global Expert Survey

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Abstract

The goal of the International Classification of Functioning is to standardize the classification of health and function of children around the world. To facilitate the application of this classification, International Classification of Functioning–based tools like the "Core Sets" are being developed. We conducted an international survey of professional experts to identify the most relevant areas of functioning in children with cerebral palsy. The questionnaire covered each component of the classification. In total, 193 professionals completed the survey (response rate 78%). Overall, 9706 answers were linked to the classification (pediatric version) by 2 professionals. From the experts' perspective, movement-related areas and social participation are the most relevant areas of functioning. Experts suggest a more comprehensive profile of functioning in particular in areas of personal capacity and social participation. The results of this survey will inform the development of the International Classification of Functioning Core Sets for children with cerebral palsy.

Keywords

cerebral palsy, expert survey, International Classification of Functioning, disability

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The International Classification of Functioning, Health and Disability,[1] provides a new conceptualization for understanding health and disability. Conceptually, "functioning," which includes body structures (anatomical parts, eg, organs, limbs), body functions (physiological functions, eg, intellectual functions), activities (execution of a task or action, eg, walking), and participation (engagement in social activities, eg, playing games), and "disability," which represents impairments, activity limitations, and participation restrictions are seen as 2 central concepts to understand health and disability.[1] In addition, contextual factors including personal (individual characteristics, eg, gender, habits, motives) and environmental factors (eg, the attitudes of the society, architectural characteristics, the legal system) interact in a positive or negative way with all the components of functioning and disability. The key contribution of the classification is that it shifts the focus from "consequences of diseases" to "functioning" and how it can be improved to achieve a productive and fulfilling life.[1] At a practical level, the International Classification of Functioning provides a universal language that clinicians and researchers can use to standardize the evaluation of functional assessments.

The International Classification of Functioning classified health domains into *categories* organized by alphanumeric codes. The categories are arranged in a stem/branch/leaf scheme within each component. The letters *b*, *s*, *d*, and *e*, which

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refer to the components (*body functions, body structure, activity and participation* and *environmental factors* respectively) of the classification, are followed by a numeric code starting with the chapter number (1 digit) followed by the second level (2 digits), and then the third and fourth levels (1 digit each). Every component consists of chapters (first level). Chapters consist of second-level categories that, in turn, are composed of categories at the third level, which include fourth-level categories.[1] For example, the component "*activity and participation*" of the classification contains the following codes: d5 for self-care (first/chapter level), d570 for looking after one's health (second level), d5702 for maintaining one's health (third level), and d57021 for seeking advice or assistance from caregivers (fourth level). In addition, the classification includes the so-called *qualifiers*, which quantify the level of functioning and health or the severity of the problem in the different categories from *body functions*, *body structures*, *activities*, and *participation*. *Environmental factors* are quantified with a negative and positive scale that denotes the extent to which an environmental factor acts as barrier or a facilitator: The World Health Organization proposes that all categories in the classification be quantified using the same generic scale (ranging from no problem to complete problem).[1] The addition of qualifiers to the categories allows a clear description of an individual functional profile.

The specific International Classification of Functioning to children consists of more than 1600 so-called categories. The large number of categories limits its utility in the clinical setting as health professionals do not find it easy to incorporate in their daily practices.[2] To improve its application, the classification must be tailored to the needs of different users, which is the primary motivation behind the development of the International Classification of Functioning Core Sets.[3,4] Specifically, the development of Core Sets uses an evidence-based methodology to identify the most relevant categories from the entire set of categories. Currently, International Classification of Functioning Core Sets have been created for different chronic conditions common to adult conditions (eg, Stroke, multiple sclerosis, Spinal Cord Injury).[4-7] The International Classification of Functioning Core Sets standardize what should be measured and reported for a given population and therefore facilitate the use of the classification system.[4] Each Core Set consists of a brief (20 to 30 categories) and a comprehensive version (70 to 100 categories). The Core Sets have been used to recognize patient's needs, to report and describe functioning in different settings (acute, rehabilitation, etc) and to assess response to interventions.[4,8,9] To date, no Core Sets have been developed for children.

Our research team in collaboration with the International Classification of Functioning Research Branch of the World Health Organization Collaborating Centre for the Family of International Classifications is leading the development of the International Classification of Functioning Core Sets (brief and comprehensive versions) for children with cerebral palsy. Following the methodology endorsed by World Health Organization for Core Sets development,[3,4] we are required to conduct 4 independent studies reflecting the professionals' perspectives, the researchers' perspectives, the children and caregivers' perspectives, and the clinical perspectives to gather the evidence to support the final selection of the categories. The findings of this international expert survey will contribute the professionals' perspectives toward the development of the Core Sets for children with cerebral palsy.

Cerebral palsy describes a group of development disorders of movement and posture commonly associated with other comorbidities (eg, sensory, cognitive, communication).[10] Cerebral palsy is associated with a heterogeneous level of disability or problems with functioning. The assessment of those problems is at the core of clinical practice in cerebral palsy, which is multidisciplinary by nature. The development of the International Classification of Functioning Core Sets for children with cerebral palsy would help standardize the clinical assessment by different professionals through the systematic use of the Core Sets. It is important to mention that the International Classification of Functioning Core Sets represent international standards for "what to measure" in relation to functioning and disability; however, they do not address "how to measure" those categories. The Core Sets will guide researchers and clinicians working with children with cerebral palsy to identify assessments tools and outcome measures (or a combination of them) that cover relevant areas of functioning and disability in this population, encouraging a more comprehensive approach that goes beyond impairments in body structures and body functions.

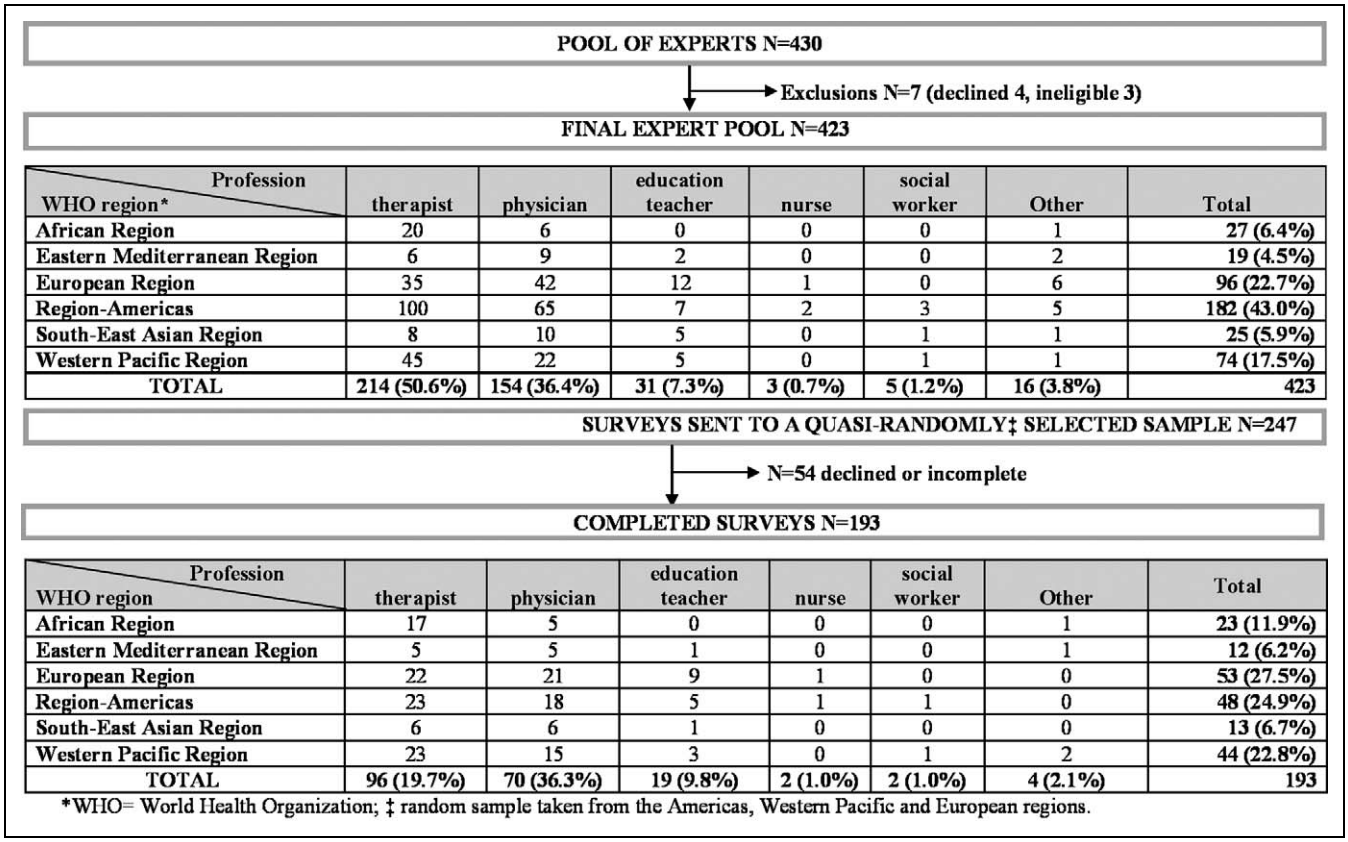
In the context of the development of the International Classification of Functioning Core Sets for cerebral palsy, the objectives of this study were (1) to identify the most relevant categories and *personal factors* for cerebral palsy from the perspective of experts, for example, health professionals, with experience treating children with cerebral palsy, and (2) to identify differences in experts' responses based on the age of the children (younger than 6 years and equal or older than 6 years). In addition, we (3) compared experts' response pattern by professional background to find out whether different professions identified a different focus in relation to the relevance of the pediatric International Classification of Functioning categories.

Methods

We conducted a cross-sectional, open-ended survey of international professional experts and adapted the methodology endorsed by the World Health Organization to develop Core Sets for children with cerebral palsy.[3,4] This study was approved by the University of British Columbia Research Ethics Board.

Study Population

Participants who met the following inclusion criteria were placed within a sample pool from which we drew a random sample for the survey: (1) has a professional background in one of the following areas: pediatrics, developmental pediatrics, pediatric rehabilitation physician, pediatric neurology, pediatric neurosurgery, orthopedic



Profession / WHO region*	therapist	physician	education teacher	nurse	social worker	Other	Total
African Region	20	6	0	0	0	1	27 (6.4%)
Eastern Mediterranean Region	6	9	2	0	0	2	19 (4.5%)
European Region	35	42	12	1	0	6	96 (22.7%)
Region-Americas	100	65	7	2	3	5	182 (43.0%)
South-East Asian Region	8	10	5	0	1	1	25 (5.9%)
Western Pacific Region	45	22	5	0	1	1	74 (17.5%)
TOTAL	214 (50.6%)	154 (36.4%)	31 (7.3%)	3 (0.7%)	5 (1.2%)	16 (3.8%)	423

Profession / WHO region	therapist	physician	education teacher	nurse	social worker	Other	Total
African Region	17	5	0	0	0	1	23 (11.9%)
Eastern Mediterranean Region	5	5	1	0	0	1	12 (6.2%)
European Region	22	21	9	1	0	0	53 (27.5%)
Region-Americas	23	18	5	1	1	0	48 (24.9%)
South-East Asian Region	6	6	1	0	0	0	13 (6.7%)
Western Pacific Region	23	15	3	0	1	2	44 (22.8%)
TOTAL	96 (19.7%)	70 (36.3%)	19 (9.8%)	2 (1.0%)	2 (1.0%)	4 (2.1%)	193

*WHO= World Health Organization; ‡ random sample taken from the Americas, Western Pacific and European regions.

Figure 1. Recruitment and sampling strategy.

surgery, occupational therapy, physiotherapy, speech and language pathology, rehabilitation nursing, social worker or special education teachers; (2) has at least 5 years of experience in working with children and youth with cerebral palsy (including clinical, educational, research, and/or administrative roles); (3) focus of practice, among those who were in practice, was primarily in pediatric physical disabilities; and (4) respondents had to be fluent in English. To ensure the development of Core Sets that reflected views of the international community, experts were recruited from the 6 World Health Organization regions: Eastern-Mediterranean, South-East Asia, Western-Pacific, the Americas, Africa, and Europe.

Sampling Methodology

Several strategies were used to recruit experts. We contacted 219 international and national organizations in the field of disability, childhood physical disability, and cerebral palsy, including the International Child Neurology Association, the Cerebral Palsy International Research Foundation, the International Association of Special Education, etc (complete list in Appendix A [available at http://jcn.sagepub.com/supplemental]). These organizations were asked to provide names and mailing lists of potential experts, who were subsequently contacted via email. Organizations that declined to release their mailing lists received a synopsis of our study, which they were asked to email to their members. An invitational letter was posted on our website (www.cfri.ca/our_research/ICF_expert_survey.asp). We sent invitational letters to all corresponding authors who published an article on cerebral palsy from 1998 to 2009 in pediatric journals. Finally, experts were asked to identify other experts whom we subsequently invited to participate.

In total, 423 professionals who met the inclusion criteria and agreed to participate in the survey constituted the expert pool from which we could sample. A stratified random sample of experts, representing each profession and each World Health Organization region, was drawn to ensure representation across professions and World Health Organization regions. Therefore, we randomly selected 25 therapists and 25 physicians from both the Americas and European regions, and 25 therapists from the Western-Pacific region. All other professionals in those regions were included, as well as all participants from the Eastern Mediterranean, South-East Asia, and African regions. In total, 247 experts were invited to participate in the survey (Figure 1).

Data Collection Protocol

The 247 experts received an email with an electronic link to the survey (Scantron survey-tool). The survey included a letter with background information and a questionnaire to complete. The participants had 6 weeks to respond and reminders were sent out by email every 2 weeks. Data collection lasted from February to April 2010. Answers were kept anonymous by assigning an identification number to each participant.

Survey Questionnaire

A self-administered questionnaire with open-ended questions was developed. The first part covered demographic information (eg, the professional background, gender, years of experience). The second part covered the International Classification of Functioning

components. The component *activity and participation* was divided into strengths and limitations. The component *environmental factors* was divided into facilitating and hindering factors. As we expected answers to differ by developmental age of the child, questions were broken down in the following age groups: younger than 6 years and equal to or older than 6 years. The content of the questionnaire was initially pilot tested with 4 experts and then reviewed by 5 content experts to refine the questions prior to administration.

Data Processing

Data collected by the survey were independently reviewed by 2 health professionals (VS, KS) to identify the themes derived from the responses. The themes (n = 9706 categories) were then linked to the pediatric International Classification of Functioning categories using established linkage rules.[11] The linkage was double coded for 50% of the themes (including all themes related to activity and participation and environmental factors) and the remaining was done only by the most senior health professional (VS). All disagreements between the 2 coders were reviewed and arbitrated by a third professional (AC). To evaluate the reliability of the linking process, the overall percentage of agreement between the 2 coders was calculated.

Using the Cieza et al linking rules,[11] all answers were first assigned a letter *b*, *s*, *d*, or *e*, which refer to the components of the classification (*body functions*, *body structures*, *activity and participation*, and *environmental factors*, respectively). Subsequently, we assigned a numeric code starting with the chapter number (1 digit). To provide more specificity, each answer was provided a second- (2 digits), third-, and fourth-level (1 digit each) code depending on the specificity of the answers. For example, the *activity and participation* component contains the following categories: d5 for self-care (first level), d530 for toileting (second level), d5300 for regulating urination (third level), and d53000 for indicating need for urination (fourth level). The component *personal factors* (pf) does not have assigned categories and codes yet. However, it was organized in main themes according to Geyh et al.[12]

Answers that were too vague and could not be assigned a second- or third/fourth-level category were only assigned a chapter level one. Finally, answers that were too general to be coded were assigned "not definable." For example, "physical health" is too general to code; therefore, it was coded as "not definable physical health." Finally, if the concept is not captured by the International Classification of Functioning classification, it was labeled "not covered."

Data Analysis

Similar to previous studies,[13-15] categories at the second level were used to identify and quantify the most relevant areas of *body functions*, *body structures*, *activity and participation*, and *environmental factors* for children with cerebral palsy. Descriptive statistics were used to describe the number of times a category was mentioned by more than 15% of the experts, the same arbitrary cut-off used in previous studies.[14,16]

To determine if patterns of answers varied by children's age group or professional background of respondents, logistic regressions were conducted using chapter-level codes as the dependent variables with age (<6 or ≥6 years) and profession as independent variables. Only professional categories with more than 50 participants (physicians and therapists) were included in the analysis. Logistic regression analyses were computed with SPSS using an alpha <0.05 to determine the significance level.

Results

Descriptive Information of the Experts

Of the 247 experts who received the survey, 193 experts completed it (response rate=78%). The majority of the experts (75%) were from the Americas, Europe, and the Western Pacific regions. The sample included a diverse group of professionals, with therapists and physicians representing 86% of the sample; the remaining included professionals working in education, nurses, and social workers (Table 1). Years of experience ranged from 5 to 44 years, with a median of 20 (Table 1).

Overview of Experts' Answers and Pediatric International Classification of Functioning Categories

In total, the answers of the survey were linked to 9706 pediatric International Classification of Functioning categories. The *body structures* (n = 1800 categories, 18.5%) and *body functions* (n = 1761 categories, 18.1%) concepts generated the most codes whereas the questions that assessed strengths on *activity and participation* (n = 917 categories, 9.4%) generated the least codes. The *personal factors* questions appeared difficult to answer as many of the answers provided were related to *environmental factors* or *body functions* and not *personal factors*. About 65% (n = 6293) of the answers were assigned second-level categories, 21% (n = 2038) were assigned third- and fourth-level categories, 12% (n = 1185) could only be assigned chapter-level categories, and less than 2% were coded as "not covered" or "not definable" (details provided in Appendixes B and C [available at http://jcn.sagepub.com/supplemental]).

The 9706 categories correspond to 182 different second-level categories: 13.2% *body structures*, 26.4% *body functions*, 37.4% *activities and participation*, and 23.0% *environmental factors*. Table 2 summarizes the second-level categories by age groups that were mentioned by at least 15% of the experts.

The answers provided by the experts covered almost all categories with the following exceptions: b8, functions of the skin and related structures, which is part of the *body functions* component; d6, domestic life, which is part of the *activity and participation* component; and e2, natural environment and human-made changes to environment, which is part of the *environmental factors* component.

As shown in Table 2, there was a high consensus among the experts on the most relevant areas of *body structures*, *body functions*, and contextual factors reflected by some categories mentioned by more than 60% of the experts. The greatest diversity among the answers was seen in the component *activity and participation*.

Comparison Between Professional Background and by Age Groups

Table 3 compares the patterns of answers at the chapter levels by professional background and by children age groups. Overall, physicians were significantly more likely to cover the "structures of the eye and ear," "structures of the

Table 1. Participant Characteristics.

Number of participants who completed the survey	193
Gender (female), %	70
Experience, median in years (IQR)	20 (15)
Experience, range in years	05-44
Professional Background Subspecialty	
Therapists, n (%)	96 (49.7)
Physiotherapist	59
Occupational therapist	24
Speech and language pathologist	12
Other	1
Physicians, n (%)	70 (36.3)
Pediatric rehabilitation physician	27
Pediatric neurologist	19
Developmental pediatrician	14
Pediatrician/neonatologist	6
Orthopedic surgeon	4
Education, n (%)	19 (9.8)
Special education teacher	9
Conductive educators	6
Early intervention teacher	2
Health teacher educator	1
Other	1
Rehabilitation nurse	2
Social worker	2
Others	4
Total	193
Working field	
Clinic	129
Research	92
Management	51
Education	94
Other	20
Affiliation[a]	
University	109
Hospital	97
Community centre	26
Office	7
Government	25
School	29
Other	32
Role of respondents' practice, n (%)	
National	48 (24.9)
Provincial	54 (28.0)
Regional	43 (22.3)
Community	33 (17.1)
None of the above	15 (7.8)
Respondent member of[a]	
Research institute	71
Professional association	166
None of the above	14

Abbreviation: IQR, interquartile range.
[a]Participants answered more than 1 option, total may not add up to 193.

cardiorespiratory system," "structures of the digestive system," "self-care," and "communication" than therapists. In contrast, physicians were significantly less likely to describe "structures related to movement," "learning and applying knowledge," "interpersonal interactions," and "support and relationships." There were no differences in the pattern of answers by professional background on the component *body functions*. In the less than 6 years age group, answers were significantly more likely to focus on "functions of the digestive system" than in the higher age group. In addition, answers related to strengths and limitations on the component of *activity and participation* were significantly more likely to cover areas of "self-care" and "mobility" for the younger age group in comparison to the older age group. A detailed description of the frequency that experts mentioned the categories included in each chapter is shown in Appendix B. For example, the main category mentioned in chapter d5 self-care was "d550-eating."

Discussion

This is the first international expert survey that explores the functional profile of children with cerebral palsy using the International Classification of Functioning framework to comprehensively catalog and describe all aspects of functioning in this population. A novel aspect of this study is the inclusion of the international community from the 6 World Health Organization regions that deals with children with cerebral palsy in the clinical, research, and educational settings. The experts described a wide spectrum of functioning and health that reflects the complexity of cerebral palsy.

Profile of Functioning by Experts' Perspective

As described by the experts, cerebral palsy affects nearly every aspect of functioning and contextual factors as there were a limited number of chapter-level categories (3 of 30) that were not mentioned in the data. The large set of pediatric International Classification of Functioning categories identified shows the high level of burden children with cerebral palsy deal with, including not only the core areas affected in cerebral palsy (gross and fine motor functioning) but its associated features (cognition, communication, behavior, sensation) and its impact on activity limitations and social participation.[10,17,18]

As expected, the vast majority of International Classification of Functioning categories in *body structures* and *body functions* represented structures and functions of movement and the nervous system. This reflects the key characteristics of cerebral palsy (abnormal motor function and motor control).[10] Furthermore, the experts acknowledged the importance of participating in leisure and recreation activities, as evidenced by the number of categories related to these areas. This is in keeping with the literature, as children with cerebral palsy have been reported to have fewer social experiences than children without disabilities.[19] Furthermore, participation of children with cerebral palsy in recreation and leisure activities has been the focus of several research studies that aimed to enhance social participation in this population.[19-23]

While experts described a comprehensive profile of functioning, by applying the International Classification of Functioning model, new insights were gained on the interaction between the child and the environment. Specifically, the experts highlighted the importance of the family as the main source of support in their immediate environment that influenced their functioning. Other research has shown a positive

Table 2. Frequencies of Pediatric International Classification of Functioning Categories Mentioned by ≥15% of the Experts.

	<6 years of age	Number of experts	% of experts		≥6 years of age	Number of experts	% of experts
Body structures							
s750	Structure of lower extremity	127	65.8	s750	Structure of lower extremity	133	68.9
s110	Structure of brain	113	58.5	s730	Structure of upper extremity	120	62.2
s730	Structure of upper extremity	104	53.9	s110	Structure of brain	90	46.6
s760	Structure of trunk	73	37.8	s120	Spinal cord and related structures	73	37.8
s770	Additional musculoskeletal structures related to movement	71	36.8	s770	Additional musculoskeletal structures related to movement	63	32.6
s220	Structure of eyeball	45	23.3	s760	Structure of trunk	47	24.4
s1[a]	Structures of the nervous system	35	18.1				
Body functions							
b7[a]	Neuromusculoskeletal and movement-related functions	127	65.8	b7[a]	Neuromusculoskeletal and movement-related functions	123	63.7
b117	Intellectual functions	69	35.8	b117	Intellectual functions	72	37.3
b167	Mental functions of language	62	32.1	b167	Mental functions of language	69	35.8
b515	Digestive functions	50	25.9	b760	Control of voluntary movement	45	23.3
b760	Control of voluntary movement	49	25.4	b280	Sensation of pain	39	20.2
b320	Articulation functions	34	17.6	b310	Voice functions	39	20.2
b210	Seeing functions	32	16.6	b164	Higher-level cognitive functions	33	17.1
b755	Involuntary movement reaction	32	16.6	b770	Gait pattern functions	31	16.1
b510	Ingestion functions	31	16.1				
b735	Muscle tone functions	31	16.1				
Activity and participation strengths							
d920	Recreation and leisure	51	26.4	d920	Recreation and leisure	44	22.8
d3[a]	Communication	40	20.7	d3[a]	Communication	34	17.6
d550	Eating	29	15.0	d820	School education	32	16.6
Activity and participation limitations							
d450	Walking	72	37.3	d920	Recreation and leisure	83	43.0
d920	Recreation and leisure	72	37.3	d820	School education	70	36.3
d3[a]	Communication	60	31.1	d5[a]	Self-care	69	35.8
d4[a]	Mobility	57	29.5	d3[a]	Communication	62	32.1
d5[a]	Self-care	56	29.0	d450	Walking	59	30.6
d550	Eating	47	24.4	d4[a]	Mobility	53	27.5
d440	Fine hand use	40	20.7	d440	Fine hand use	29	15.0
d330	Speaking	31	16.1				
d455	Moving around	31	16.1				
Environmental factors supportive							
e310	Immediate family	135	69.9	e310	Immediate family	113	58.5
e355	Health professionals	88	45.6	e355	Health professionals	77	39.9
e580	Health services, systems, and policies	74	38.3	e585	Education and training services, systems, and policies	59	30.6
e585	Education and training services, systems, and policies	38	19.7	e580	Health services, systems, and policies	50	25.9
				e115	Products and technology for personal use in daily living	39	20.2
Environmental factors barriers							
e580	Health services, systems, and policies	63	32.6	e460	Societal attitudes	74	38.3
e150	Design, construction, and building products and technology of buildings for public use	52	26.9	e150	Design, construction, and building products and technology of buildings for public use	63	32.6
e310	Immediate family	48	24.9	e355	Health professionals	59	30.6
e355	Health professionals	44	22.8	e585	Education and training services, systems, and policies	49	25.4
e460	Societal attitudes	40	20.7	e570	Social security services, systems, and policies	43	22.3
e570	Social security services, systems, and policies	35	18.1	e580	Health services, systems, and policies	42	21.8
e165	Assets	34	17.6	e310	Immediate family	32	16.6
e585	Education and training services, systems, and policies	29	15.0	e165	Assets	31	16.1
Personal factors							
na[b]	General patterns of experience and behavior	20	38.6	na	General patterns of experience and behavior	19	36.5
na	Biographical, sociodemographic, and economic factors	10	19.8	na	Biographic, sociodemographic, and economic factors	13	25.9

Abbreviation: ICF-CY, International Classification of Functioning, Children & Youth Version.
[a]Answers were too general, only chapter-level categories were assigned.
[b]Categories not assigned in the ICF-CY.

Table 3. Professional Background and Age-Group Comparisons: ICF-CY Component Chapter-Level Comparisons.

ICF-CY chapters		Professional background (physician vs therapist) OR (95% CI); *P*-value	Age group (<6 years vs ≥6 years) OR (95% CI); *P*-value
Body structures			
s1	Structures of the nervous system	1.25 (0.98, 1.59); .07	0.91 (0.72, 1.16); .46
s2	The eye, ear, and related structures	2.35 (1.52, 3.64); .00*	1.42 (0.93, 2.19); .10
s3	Structures involved in voice and speech	0.77 (0.46, 1.28); .31	1.51 (0.92, 2.48); .10
s4	Structures of the cardiovascular, immunological, and respiratory systems	4.34 (1.94, 9.74); .00*	0.84 (0.47, 1.50); .55
s5	Structures related to the digestive, metabolic, and endocrine system	2.07 (1.02, 4.23); .04*	1.29 (0.64, 2.62); .47
s6	Structures related to the genitourinary and reproductive systems	4.21 (0.44, 40.54); .21	0.33 (0.03, 3.20); .34
s7	Structures related to movement	0.79 (0.64, 0.97); .02*	0.93 (0.75, 1.14); .46
Body functions			
b1	Mental functions	1.03 (0.82, 1.29); .82	0.80 (0.64, 1.00); .05
b2	Sensory functions and pain	1.02 (0.72, 1.43); .92	0.98 (0.70, 1.36); .88
b3	Voice and speech functions	1.04 (0.65, 1.68); .85	0.96 (0.60, 1.54); .87
b4	Functions of the cardiovascular, immunological, and respiratory systems	0.52 (0.25, 1.07); .07	0.75 (0.39, 1.45); .39
b5	Functions of the digestive, metabolic, and endocrine systems	1.07 (0.74, 1.54); .71	2.16 (1.47, 3.17); .00*
b6	Genitourinary and reproductive functions	1.41 (0.35, 5.68); .62	0.33 (0.07, 1.63); .17
b7	Neuromusculoskeletal and movement-related functions	0.96 (0.78, 1.18); .71	1.12 (0.91, 1.37); .29
Activity and participation—strengths			
d1	Learning and applying knowledge	0.59 (0.38, 0.92); .02*	1.37 (0.65, 2.91); .41
d2	General tasks and demands	0.75 (0.19, 3.02); .68	0.44 (0.04, 4.96); .50
d3	Communication	1.58 (1.05, 2.36); .02*	0.76 (0.39, 1.48); .42
d4	Mobility	0.88 (0.62, 1.24); .45	1.24 (0.69, 2.24); .46
d5	Self-care	1.86 (1.23, 2.8); .00*	1.75 (1.15, 2.65); .00*
d6	Domestic life	6.08 (0.68, 54.64); .10	NA
d7	Interpersonal interactions and relationships	0.51 (0.32, 0.81); .00*	1.39 (0.63, 3.07); .41
d8	Major life areas	1.62 (0.88, 2.96); .11	0.35 (0.18, 0.69); .00*
d9	Community, social, and civic life	0.75 (0.48, 1.16); .19	0.68 (0.35, 1.31); .24
Activity and participation—limitations			
d1	Learning and applying knowledge	1.11 (0.70, 1.74); .66	0.86 (0.55, 1.35); .51
d2	General tasks and demands	1.74 (0.53, 5.74); .36	0.59 (0.17, 2.02); .39
d3	Communication	1.54 (1.09, 2.19); .01*	1.32 (0.93, 1.87); .12
d4	Mobility	0.86 (0.68, 1.10); .24	1.47 (1.15, 1.87); .00*
d5	Self-care	1.32 (0.99, 1.76); .06	1.36 (1.02, 1.81); .03*
d6	Domestic life	0.36 (0.08, 1.70); .19	0.11 (0.01, 0.90); .03*
d7	Interpersonal interactions and relationships	0.61 (0.33, 1.12); .11	0.80 (0.45, 1.42); .45
d8	Major life areas	0.99 (0.66, 1.50); .97	0.37 (0.24, 0.58); .00*
d9	Community, social, and civic life	0.76 (0.54, 1.07); .11	0.73 (0.53, 1.02); .06
Environmental factors—supportive			
e1	Products and technology	0.83 (0.6, 1.15); .25	0.87 (0.64, 1.20); .39
e3	Support and relationships	0.68 (0.53, 0.86); .00*	1.15 (0.91, 1.47); .25
e4	Attitudes	1.32 (0.75, 2.33); .33	1.10 (0.63, 1.95); .73
e5	Services, systems, and policies	1.71 (1.31, 2.24); .00*	0.86 (0.66, 1.12); .26
Environmental factors—barriers			
e1	Products and technology	1.00 (0.75, 1.33); .98	1.09 (0.83, 1.44); .54
e2	Natural environment and human-made changes to environment	0.39 (0.11, 1.40); .14	0.96 (0.34, 2.65); .93
e3	Support and relationships	1.05 (0.78, 1.42); .75	1.01 (0.75, 1.36); .94
e4	Attitudes	1.13 (0.83, 1.54); .44	1.03 (0.76, 1.39); .87
e5	Services, systems, and policies	0.89 (0.68, 1.15); .36	0.94 (0.73, 1.20); .61

Abbreviations: ICF-CY, International Classification of Functioning, Children & Youth Version; NA, not applicable, not tested due to low numbers of categories
[a]Chapters s8, skin and related structures; b8, functions of the skin and related structures; and e2, natural environment and human-made changes to environment (supportive factors), were not tested because of low numbers of categories.
*P-value < .05

association between parents' health and the physical functioning of their children with cerebral palsy,[24] illustrating the relationship between the child's immediate environment (family) and the child's functional capacity. Moreover, aspects of the child's environmental experiences were frequently mentioned including environmental barriers related to accessibility of public buildings, availability of heath professionals, and educational training programs.

Although experts agreed on many relevant areas of functioning in the components *body structures*, *body functions*, and *environmental factors*, experts with different professional backgrounds highlighted different areas of functioning.

Physicians were more likely to address areas of *body structures* and some areas of *activity and participation* whereas therapists mainly focused on areas of *activity and participation*. This emphasizes the need of a multidisciplinary approach when selecting candidate International Classification of Functioning Core Sets categories. Importantly, different professional perspectives will contribute to the development of more comprehensive International Classification of Functioning Core Sets, the use of which will ultimately guide the systematic assessment of children with cerebral palsy.

Our findings may also suggest the need to create age-specific International Classification of Functioning Core Sets for children with cerebral palsy, with tailored sets of categories in the components *body functions* and *activity and participation*. For example, categories covering functions of the digestive system were more prevalent in the younger group. This reflects the prevalence of feeding difficulties and oral motor dysfunction in young children with cerebral palsy.[25,26] By describing age-specific functional profiles, experts acknowledged the developmental consequences of the functional limitations associated with cerebral palsy that are important to consider for maximizing their functional potential.[23,27]

To our knowledge, only 1 study to date applied the International Classification of Functioning categories to assess domains of importance in therapeutic interventions for children with cerebral palsy.[28] The Vargus-Adams study conducted a survey of youths, parents, and medical professionals ($n = 75$). Out of 322 responses, the most prevalent categories were related to "mobility" (45%) and "movement related functions" (45%). In line with our findings, their results demonstrate the multiple concerns regarding the spectrum of functioning and health in children with cerebral palsy. The current study provides a more comprehensive description of functioning in children with cerebral palsy by including a large multidisciplinary group of professionals and by applying the International Classification of Functioning framework as well as its coding system in a more rigorous way.

In this study, we have identified the most relevant areas of functioning in children with cerebral palsy based on experts' perspectives, using the International Classification of Functioning language. The most prevalent areas described by the experts were related to structures and functions of movement, social participation and family support. A comprehensive list of categories covering all International Classification of Functioning components was described. The list of International Classification of Functioning categories identified in this study can inform professionals working with children with cerebral palsy on what key areas to consider when assessing this population. Furthermore, our findings will provide 1 piece of evidence toward the development of the International Classification of Functioning Core Sets for children with cerebral palsy. As professionals' perspectives might differ from the views of children with cerebral palsy or their caregivers, we are currently conducting a qualitative study to address the clients' perspectives on relevant areas of functioning.

Applying the International Classification of Functioning Core Sets for Children With Cerebral Palsy in Clinical Practice and Research

The brief and comprehensive versions of the International Classification of Functioning Core Sets for children with cerebral palsy will facilitate a systematic and comprehensive description of functioning in clinical practice and research. The brief Core Set (20-30 categories) will include as few categories as possible to be practical, but as many as necessary to be sufficiently comprehensive in describing the typical challenges in functioning of children with cerebral palsy. The brief Core Set is meant to be used in regular clinical encounters and clinical studies. It will guide the selection of assessment and outcome measures that align with the categories included in the Core Set. The comprehensive Core Set (70-100 categories) is meant to be used in multidisciplinary assessments. The goal of this Core Set is to promote all team members to use the same language "the International Classification of Functioning categories" when describing functioning. Again appropriate assessment tools need to be selected or a combination of them to cover the categories included in this Core Set. To use the common language of the International Classification of Functioning, the original technical terminology of the clinical assessment tools has to be translated or "linked" to the corresponding International Classification of Functioning categories using established linking rules.[11] In addition, all team members need to consider every potentially relevant aspect of functioning, even in areas of functioning where experts are not specialists. Finally, as we anticipate that no unique assessment tool or outcome measure will fully cover the categories included in the final Core Sets for children with cerebral palsy, our findings may guide the development of an International Classification of Functioning Core Set–based measure for this population.

Limitations

The findings of this study should be interpreted in light if its limitations. Firstly, some participants encountered technical difficulties during the data collection (eg, poor internet connectivity) which limited enrollment and participation of experts from Africa, reducing the representativeness of the sample in that region. Second, we limited the number of age groups in our study to 2; adding more age groups might have resulted in categories related to more developmental issues. Thirdly, despite our efforts some professional groups were underrepresented (eg, nurses, social workers). Finally, some respondents were not very familiar with the International Classification of Functioning components and found some questions challenging to answer (ie, personal factors). This suggests that there is a need to disseminate the knowledge and use of the International Classification of Functioning among professionals working with children with cerebral palsy.

In conclusion, an international group of experts provided a comprehensive profile of functioning for the cerebral palsy population, in particular, in the areas of personal capacity and

social participation, as well as a detailed description of relevant contextual factors. Our findings provide a novel approach to describing functioning in children with cerebral palsy. The results have the potential to facilitate the systematic application of the International Classification of Functioning in this population.

Authors' Note

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Author Contributions

VS, AC, MO, and RA designed the study. VS, KS, and MO performed data collection. VS, AC, and KS were responsible for data analysis. VS, LM, AC, and MO interpreted the data. VS performed the statistical analysis and, along with LM, wrote the manuscript. LM, AC, AK, KS, MO, and RA reviewed the manuscript for intellectual content and were responsible for critically revising the manuscript. RA mentored all authors.

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Ethical Approval

This study was approved by the University of British Columbia Research Ethics Board. (CW09-0123 / H09-01287)

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