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ORIGINAL REPORT

DEVELOPING AN ICF CORE SET FOR ADULTS WITH CEREBRAL PALSY: A GLOBAL EXPERT SURVEY OF RELEVANT FUNCTIONS AND CONTEXTUAL FACTORS*

Chonnanid LIMSAKUL, MD[1,2], Suzie NOTEN, MSc[1,3], Melissa SELB, MSc[4,5], Henk J. STAM, MD, PhD[1], Wilma M. A. VAN DER SLOT, MD, PhD[1,3] and Marij E. ROEBROECK, PhD[1,3]

From the [1]Department of Rehabilitation Medicine, Erasmus University Medical Center, Rotterdam, The Netherlands, [2]Department of Orthopedic Surgery and Rehabilitation Medicine, Prince of Songkla University, Songkhla, Thailand, [3]Rijndam Rehabilitation, Rotterdam, The Netherlands, [4]Swiss Paraplegic Research, [5]ICF Research Branch, a cooperation partner within the WHO-FIC Collaborating Centre in Germany (at DIMDI), Nottwil, Switzerland

Objective: **To identify areas of functioning in adults with cerebral palsy that are considered relevant by experts, in order to develop an International Classification of Functioning, Disability and Health (ICF) Core Set for adults with cerebral palsy.**

Participants: **Experts from various professional backgrounds worldwide who had experience working with adults with cerebral palsy for ≥2 years and were able to complete the survey in the English language.**

Methods: **A cross-sectional study using an international internet-based survey. The experts were asked to address relevant areas of functioning in adults with cerebral palsy. These areas of functioning were then linked to the ICF and the frequencies analysed.**

Results: **A total of 126 experts from 32 countries completed the survey. From the responses, 217 unique second-level ICF categories were identified. The three most frequently mentioned categories were "design, construction and building products and technology of buildings for public use (e150, 77%) and private use" (e155, 67%), followed by "sensation of pain" (b280, 62%).**

Conclusion: **The broad diversity of ICF categories reported by the experts emphasize the known heterogeneity of cerebral palsy and the variety of functioning in adulthood. They also reported on many environmental factors, illustrating the importance of person-environment interactions. These findings provide information about relevant issues for use in developing an ICF Core Set for adults with cerebral palsy.**

Key words: adults; cerebral palsy; ICF; ICF Core Set; expert survey.

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Correspondence address: Chonnanid Limsakul, Erasmus University Medical Center, Department of Rehabilitation Medicine, PO Box 2040, NL-3000 CA Rotterdam, The Netherlands. E-mail: lchonnan@medicine.psu.ac.th

LAY ABSTRACT

Nowadays the population of persons with cerebral palsy is mostly at adult age. The clinical care and research for this understudied population would benefit from standardized outcomes. Therefore, we aim to develop an International Classification of Functioning, Disability and Health Core Set for adults with cerebral palsy, integrating knowledge from several perspectives. One of these perspectives is the experts' view, which we studied in a survey among professionals working with adults with cerebral palsy worldwide. Professional experts indicated over 200 relevant aspects of functioning for adults with cerebral palsy, covering a broad variety. They most often reported problems for adults with cerebral palsy in mobility or having pain, and on the hindrance of construction and technology of public or private buildings for their functioning. The present results emphasize the known heterogeneity of cerebral palsy and the large number of impairments and activity limitations in adulthood. Also, experts underlined the importance of person-environment interactions, by frequently naming environmental factors.

The framework of the International Classification of Functioning, Health, and Disability (ICF) describes the functions and disabilities of individuals (1). According to the ICF model, all aspects of life can be addressed by defining 5 ICF components: *Body functions, Body structures, Activities and participation, Environmental factors and Personal factors*. The ICF is considered useful in assessing outcomes in persons with any health condition, and thereby serves as a common language across healthcare disciplines and countries. However, a lack of knowledge of the ICF may hamper its use in clinical practice (2). Moreover, since there are more than 1,400 ICF items, its application in patient care is challenging. To overcome these problems, ICF Core Sets are developed, which contain a comprehensive list of ICF categories for a specific health condition (3, 4). ICF Core Sets for more than 30 health conditions have been developed (4), including an ICF Core Set for children with cerebral palsy (CP) (5).

CP is a disorder of movement and posture caused by disturbances of the immature brain during infancy

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or childhood (6). CP also affects other body functions and activities, such as intellectual functions and communication (7, 8). With a prevalence of 2–3 per 1,000 live births (9), CP is the most common cause of physical disability in children. In US, 85% of children with CP are expected to survive into adulthood and, as there is no cure for CP, their disabilities will endure or worsen (8). New health issues and activity limitations may arise as their life situations change, such as increased fatigue or employment problems (10, 11) and thus an ICF Core Set developed for children might not fully cover all issues experienced by adults with CP. Therefore, we are developing an ICF Core Set for adults with CP, which will cover all relevant areas of functioning in adulthood.

Due to increasing life expectancy, the number of adults with CP and their use of healthcare have increased. Nowadays, many organizations for childhood disabilities, such as the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM), focus not only on children, but also on adults with CP. Moreover, the number of publications on the impact of CP in adulthood have increased over the past 20 years, addressing a variety of research topics (12).

In order to develop an ICF Core Set scientific evidence is collected from 4 perspectives, by means of a systematic literature review (research perspective), a qualitative study (perspectives of persons with the health condition), an expert survey (professional perspectives), and an empirical multicentre study (clinical perspectives). In the second phase professional experts in adults with CP will reach consensus on a final ICF Core Set for adults with CP, which will be validated and implemented in different settings.

This study reports the results of a worldwide expert survey of professionals with experience in working with adults with CP. The objectives of the study were: (*i*) to identify the most relevant ICF categories in adults with CP, addressed by health professionals and researchers, and (*ii*) to compare the response patterns between experts from different backgrounds and different countries (13).

METHODS

A cross-sectional survey using an internet-based questionnaire was conducted among worldwide experts on adults with CP. The methodology followed the guidelines of the World Health Organization (WHO) ICF Research Branch for the development of an ICF Core Set (4).

Study population

Clinical professionals and researchers were recruited from 6 WHO world regions: Africa, South-East Asia, Eastern Mediterranean, Europe, Western Pacific, and Region of the Americas (North, Middle and South). The inclusion criteria were: (*i*) professional background in one of the following areas: medicine (rehabilitation medicine, paediatrics, neurology or orthopaedic surgery), physical therapy, occupational therapy, psychology, speech or language therapy, nursing, social work, research or related field, such as exercise physiology; (*ii*) at least 2 years of experience in working with adults with CP aged ≥18 years; and (*iii*) sufficient knowledge of English to complete the survey.

Recruitment methodology

To ensure the survey represented perspectives from all 6 WHO world regions, experts were recruited using several strategies (13–15). Emails were sent to contact persons from international/national organizations in the fields of CP, disability, rehabilitation medicine and physical therapy, requesting them to identify experts in their organizations who worked with adults with CP. Emails were also sent to dedicated research groups and clinical expert groups for adults with CP in order to identify eligible experts in this field, such as the Lifespan Care Committee of the AACPDM. In addition, the names of corresponding authors were extracted from research studies on adults with CP from 2000 to 2017, identified in a previous systematic review (12). To create snowball sampling, all of the identified experts were asked to recommend other professionals from their network. The expert survey was announced to the attendees of 2 international conferences in 2018: the AACPDM Annual Meeting and the International Society of Physical and Rehabilitation Medicine (ISPRM) World Congress, and on the website of the ICF research branch (https://www.icf-research-branch.org/).

Data collection protocol

All identified experts received an invitation to participate in the survey. They were provided with a link to the closed-access survey and detailed instructions on how to complete the survey. A link to an open-access survey was provided to those experts inviting additional colleagues to join the survey. Participants gave online informed consent to participate in the study. The respondents were asked to complete the survey within 6 weeks, and a reminder was sent 2 weeks before the deadline. To ensure the sample adequately represented the 6 WHO world regions, a second reminder was sent to the identified experts in the African and Western Pacific regions, since the responses from these regions were very low. Data were collected between October 2018 and January 2019.

Survey questionnaire

An internet-based questionnaire was developed using LimeSurvey. The first part covered the participant's demographic data, such as sex, professional background, and years of experience in working with adults with CP. The second part included 6 open-ended questions about the most relevant problems of adults with CP from the expert's perspective. These questions addressed the ICF components *Body functions* (b), *Body structures* (s), *Activities and participation* (d), *Environmental factors* (e), and *Personal factors*. For *Environmental factors,* supportive and hindering factors were distinguished (4, 16) (Table I).

Linking to the ICF

Meaningful concepts, which were extracted from the expert's answers (4), were linked to the most precise ICF categories according to the refined linking rules set out by Cieza et al. (17). The meaningful concepts were assigned to an ICF component denoted by letters, as follows: "b": *Body functions;* "s": *Body structures;* "d": *Activities and participation;* "e": *Environmental*

Table I. Open-ended questions in the expert survey

In your experience with adults with CP, what are the problems in body functions (including mental functions) they experience?
In your experience with adults with CP, which parts of their body (brain included) are affected?
In your experience with adults with CP, what are the difficulties/challenges they experience in their everyday activities and involvement in society?
In your experience with adults with CP, what about their environment and living conditions might be supportive for them?
In your experience with adults with CP, what about their environment and living conditions might be hindering for them?
In your experience with adults with CP, which personal factors are important for them and the way they handle their CP?

CP: cerebral palsy.

factors. The numeric codes following the letters were arranged hierarchically. In this system, the first digit indicates a chapter level, e.g. b1 for "mental functions". Further numbers are added for a more specific category, 2 digits for the second level (e.g. b114 "Orientation functions"), and one additional digit each for the third level (b1142 "Orientation to person") and fourth level (b11420 "Orientation to self"). A meaningful concept can include one or more ICF categories. Although Personal factors are not yet classified in the ICF, they refer to important factors related to an individual, such as self-efficacy, socioeconomic status and were labelled as "pf" items according to Cieza et al. (17).

Answers that were too general to be linked to an ICF category, such as general health, were coded as *not defined*. The answers that did not belong to the ICF universe, e.g. quality of life, were labelled as *not covered*.

All answers were linked by the first author (CL). To ensure the accuracy of the linking procedure, 50% of the answers were independently linked by a second researcher (SN). Both researchers had previously completed the E-learning ICF tool and received additional linking training from the ICF research branch coordinator (MS). To ensure the consistency of linking results, the first 2 surveys were linked and discussed before the remaining surveys were analysed. The linking results of both researchers were compared, and disagreements between the 2 linkers were discussed until resolved. If consensus could not be reached, a third person (MR) was consulted to make a decision. The inter-rater agreement of the linking process was calculated on the second-level ICF categories, prior to reaching consensus between the linkers, in case of disagreement, using Cohen's kappa (18).

Data analysis

ICF categories were analysed at the second level. All the third- and fourth-level categories were aggregated to their corresponding second level. If a second-level category was presented repeatedly by one participant, it was counted only once. Frequency analysis was used to analyse the categories reported by the experts. Categories indicated by at least 15% of the experts were included in the description of ICF categories for a consensus meeting (13).

Differences in response patterns between experts from different clinical backgrounds (dichotomized as physicians vs therapists) and countries with different income levels according to gross national income per capita (19) (dichotomized as low- and middle-income vs high-income countries) were evaluated using logistic regression analysis, with professional background and country income as independent variables, corrected by years of working experience with adults with CP. One participant who chose both a physician and therapist background was excluded from this analysis ($n=1$) and the researcher group was excluded from the analysis due to the small number of respondents identified in this subsample ($n=10$). Only categories that were reported by at least 50 respondents were included in the analysis. The study analysis was performed by using SPSS version 24.0. To correct for multiple testing, we used a significance level with Bonferroni correction of $p<0.0025$.

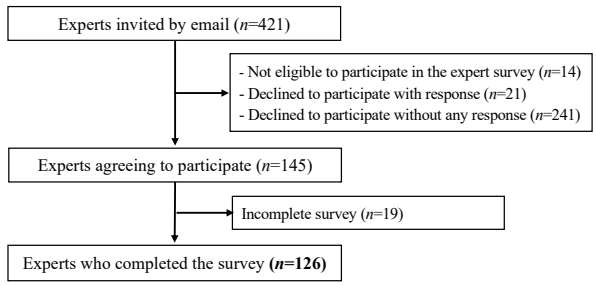

Fig. 1. Flow diagram of the recruitment process.

RESULTS

Descriptive information from the experts

Of the 421 experts approached to participate in the study, 126 experts from 32 countries completed the survey (Fig. 1). Table II shows the characteristics of the experts; they mostly had many years of working

Table II. Characteristics of experts ($n=126$)

Characteristics	
Age, years, median (IQR)	45 (39–56)
Years of experience, median (IQR)	12 (8–22)
Sex ($n=125$), *n* (%)	
Male	32 (25.6)
Female	93 (74.4)
WHO Region ($n=126$), *n* (%)	
Africa	3 (2.4)
America	39 (31.0)
South-East Asia	14 (11.1)
Europe	57 (45.2)
Eastern Mediterranean	4 (3.2)
Western Pacific	9 (7.1)
Working field ($n=126$), *n* (%)	
Clinical setting	78 (61.9)
Disability care	7 (5.6)
Management	6 (4.8)
Research	18 (14.3)
Education	14 (11.1)
Others	3 (2.4)
Professional background subspecialty ($n=167$), *n* (%)	
Physician	72 (43.1)[a]
Rehabilitation physician	56
Neurologist/neurosurgeon	1
Orthopaedic surgeon	4
Paediatrician	3
Physician for people with intellectual disability	6
General practitioner	2
Therapist/nurse	49 (29.3)[a]
Physiotherapist	29
Occupational therapist	9
Speech and language therapist	6
Rehabilitation nurse	1
Social worker	2
Other	2
Researcher	39 (23.4)[a]
Other	7 (4.2)[a]

[a]Participants could choose more than one professional background.
WHO: World Health Organization; IQR: interquartile range.

experience with adults with CP, and represent 3 types of professional background: physicians, therapists/nurses and researchers.

Overview of the experts' answers and linking results

From the 126 completed questionnaires, a total of 6,121 meaningful concepts were extracted, which were linked to 7,370 ICF categories. Overall, 3,545 (48.1%) concepts were linked to second-level ICF categories, 2,178 (29.6%) were assigned to third- and fourth-level ICF categories, and 840 (11.4%) were identified at the chapter level. A total of 251 (3.4%) *personal factors,* 411 (5.6%) *non-definable codes*, and 145 (2.0%) *not covered codes* were identified. A Cohen's kappa of 0.72 (95% confidence interval (95% CI) 0.70–0.73) indicated good inter-rater agreement between the independent linkers.

In total, 217 unique second-level ICF categories were identified, among which the largest number were allocated to *Environmental factors* (34.0%), followed by *Body functions* (22.0%), *Activities and participation* (21.0%) and *Body structures* (12.2%). The most frequently mentioned categories were 63 second-level categories, reported by at least 15% of the experts and 5 *Personal factors*, indicated by ≥10% (Table III). Fig. 2 shows those categories indicated by ≥30% of the experts.

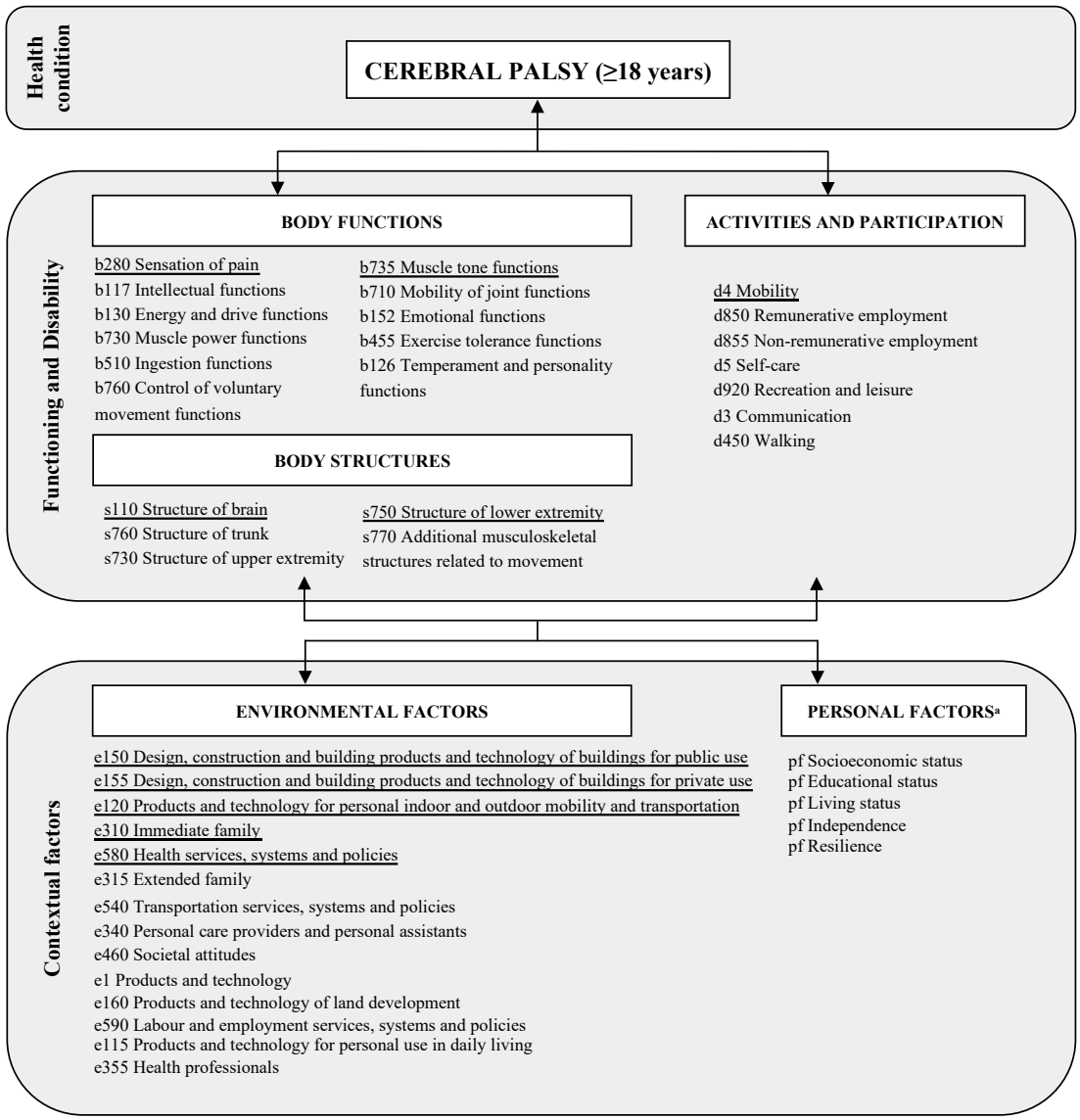

Fig. 2. International Classification of Functioning, Disability and Health (ICF) framework, including the ICF categories reported by ≥30% of the experts. Those identified by ≥50% of the experts are underlined. [a]Personal factors reported by ≥10% are presented.

Table III. Relative frequency of International Classification of Functioning, Disability and Health (ICF) categories mentioned by ≥15% of the experts (n=126)

ICF code	ICF category description	Experts n (%)
b	***Body functions***	
b280	Sensation of pain	78 (61.9)
b735	Muscle tone functions	71 (56.4)
b117	Intellectual functions	61 (48.4)
b710	Mobility of joint functions	56 (44.4)
b130	Energy and drive functions	55 (43.7)
b152	Emotional functions	55 (43.7)
b730	Muscle power functions	49 (38.9)
b455	Exercise tolerance functions	44 (34.9)
b510	Ingestion functions	42 (33.3)
b126	Temperament and personality functions	38 (30.2)
b760	Control of voluntary movement functions	38 (30.2)
b7	Neuromusculoskeletal and movement-related functions	37 (29.4)
b210	Seeing functions	28 (22.2)
b3	Voice and speech functions	24 (19.1)
b164	Higher-level cognitive functions	23 (18.3)
b525	Defecation functions	22 (17.5)
b1	Mental functions	21 (16.7)
b620	Urination functions	21 (16.7)
b320	Articulation functions	20 (15.9)
b440	Respiration functions	20 (15.9)
b770	Gait pattern functions	20 (15.9)
b156	Perceptual functions	19 (15.1)
b765	Involuntary movement functions	19 (15.1)
s	***Body structures***	
s110	Structure of brain	76 (60.3)
s750	Structure of lower extremity	72 (57.1)
s760	Structure of trunk	60 (47.6)
s730	Structure of upper extremity	58 (46.0)
s770	Additional musculoskeletal structures related to movement	48 (38.1)
s7	Structures related to movement	36 (28.6)
s430	Structure of respiratory system	22 (17.5)
s710	Structure of head and neck region	22 (17.5)
s320	Structure of mouth	21 (16.7)
s5	Structures related to the digestive, metabolic and endocrine systems	21 (16.7)
d	***Activities and participation***	
d4	Mobility	87 (69.1)
d850	Remunerative employment	61 (48.4)
d855	Non-remunerative employment	58 (46.0)
d5	Self-care	52 (41.3)
d920	Recreation and leisure	49 (38.9)
d3	Communication	47 (37.3)
d450	Walking	41 (32.5)
d9	Community, social and civic life	37 (29.4)
d7	Interpersonal interactions and relationships	36 (28.6)
d470	Using transportation	33 (26.2)
d770	Intimate relationships	33 (26.2)
d440	Fine hand use	30 (23.8)
d510	Washing oneself	26 (20.6)
d845	Acquiring, keeping and terminating a job	25 (19.8)
d550	Eating	24 (19.1)
d240	Handling stress and other psychological demands	22 (17.5)
d540	Dressing	21 (16.7)
d570	Looking after one's health	21 (16.7)
d530	Toileting	19 (15.1)
e	***Environmental factors***	
e150	Design, construction and building products and technology of buildings for public use	97 (77.0)
e155	Design, construction and building products and technology of buildings for private use	84 (66.7)
e120	Products and technology for personal indoor and outdoor mobility and transportation	74 (58.7)
e310	Immediate family	70 (55.6)
e580	Health services, systems and policies	66 (52.4)
e315	Extended family	60 (47.6)
e540	Transportation services, systems and policies	58 (46.0)
e340	Personal care providers and personal assistants	52 (41.3)
e460	Societal attitudes	43 (34.1)
e1	Products and technology	42 (33.3)
e160	Products and technology of land development	42 (33.3)
e590	Labour and employment services, systems and policies	42 (33.3)
e115	Products and technology for personal use in daily living	41 (32.5)
e355	Health professionals	38 (30.2)
e3	Support and relationships	36 (28.6)
e135	Products and technology for employment	35 (27.8)
e555	Associations and organizational services, systems and policies	35 (27.8)
e525	Housing services, systems and policies	32 (25.4)
e575	General social support services, systems and policies	31 (24.6)
e140	Products and technology for culture, recreation and sport	27 (21.4)
e5	Services, systems and policies	26 (20.6)
e125	Products and technology for communication	23 (18.3)
e320	Friends	21 (16.7)
e585	Education and training services, systems and policies	21 (16.7)
pf	***Personal factors***[a]	
	Personal factors, socioeconomic status	18 (14.3)
	Personal factors, educational status	17 (13.5)
	Personal factors, living status	17 (13.5)
	Personal factors, independence	16 (12.7)
	Personal factors, resilience	13 (10.3)
nc	***Not covered***[b]	
	Not covered, health condition	53 (42.1)
nd	***Not defined***[c]	
	Not defined, accessibility	33 (26.2)
	Not defined, mental health	20 (15.9)

Categories are ordered according to their relative frequency within each component. [a]Personal factors mentioned by ≥ 10% of experts. [b]Items not covered by the ICF. [c]Items too general to be linked to an ICF category or a personal factor.

For *Body functions*, categories in all 8 ICF chapters were identified, mostly addressing "Sensation of pain" and "Muscle tone functions"'. The answers provided by the experts on *Body structures* also covered all 8 ICF chapters, with most of the categories identified in "Structures of the nervous system" and "Structures related to movement". For *Activities and participation*, the highest-rated second-level categories by experts for adults with CP were related to "Mobility" and "Employment".

A large number of categories involved *Environmental factors*, of which "Design of buildings for public or private use" and "Products and technology for mobility and transportation" were most often indicated. In addition, experts frequently reported on the importance of the immediate family and healthcare services for functioning of adults with CP. Notably, these categories were reported as both facilitators and barriers for functioning (Table IV).

Comparison between professional backgrounds

Table V compares the response patterns of the frequently addressed second-level ICF categories between physicians and therapists, and between experts from low- and middle-income vs high-income countries.

The patterns of answers did not differ between physicians and therapists. When considering country income, the experts from low- and middle-income countries were significantly less likely to report "Sensation of pain" (b280) than the experts from high-income countries.

DISCUSSION

This study surveyed expert opinions on the important areas of functioning for adults with CP, in order to contribute to the development of an ICF Core Set for adults with CP. The professional experts surveyed, all of whom were working with adults with CP, identified a large number of categories in *Body functions* and *Body structures*, which reflect the nature of CP affecting several body systems (6). "Sensation of pain" was the most frequently addressed category of *Body functions*, which is in line with present knowledge showing that 71% of adults with CP experience pain in at least one part of the body (20). Also, in research among adults with CP, pain is the most commonly studied issue (12). This reflects the increased attention of professionals on pain during the last decade. Moreover, a large number of categories addressed the musculoskeletal and nervous systems; for example, "Muscle tone functions", and "Structure of brain", which is compatible with the definition of CP (6). Notably, most experts (78.6%) reported mental or physical fatigue as important impairments for adults with CP; these were categorized as "Energy and drive functions" or "Exercise tolerance functions", respectively (21). The experts also often reported "depression", a common mood disorder in persons with disabilities (22, 23), which we linked to "Emotional functions". As expected, "Remunerative and Non-remunerative employment" were the most frequent second-level categories addressed for *Activities and participation*, since these represent an important life area in adulthood (11, 24). In addition, the experts often focused on basic activities of daily living by using general terms, which were linked to the ICF chapters "Mobility" and "Self-care".

The largest number of categories that the experts addressed for adults with CP were *Environmental factors*. Mostly, they reported these categories related to body impairments and activity limitations, for example, *"Practicing sports and attending social activities: if the person does not have accessible transportation and public places that allow the use of wheelchairs or other aids, they can't do these activities"*. These comments underline the importance of person-environment interactions. The experts also often addressed "Products and technology", especially the design of buildings and mobility devices, which are essential for adults with CP in order to live independently and may support community participation. Furthermore, according to the professionals "Supportive people and relationships" seemed to be an important factor for functioning of adults with CP. In the present study, immediate families were identified as the most important persons for adults with CP, since many of them still lived with their pa-

Table IV. The most frequently reported environmental factors reported as a facilitator or barrier by ≥ 15% of experts

Facilitator		Experts *n* (%)	Barrier		Experts *n* (%)
e150	Design, construction and building products and technology of buildings for public use	72 (57.1)	e150	Design, construction and building products and technology of buildings for public use	71 (56.4)
e155	Design, construction and building products and technology of buildings for private use	63 (50.0)	e155	Design, construction and building products and technology of buildings for private use	53 (42.1)
e120	Products and technology for personal indoor and outdoor mobility and transportation	52 (41.3)	e120	Products and technology for personal indoor and outdoor mobility and transportation	42 (33.3)
e310	Immediate family	36 (28.6)	e540	Transportation services, systems and policies	37 (29.4)
e580	Health services, systems and policies	36 (28.6)	e580	Health services, systems and policies	34 (27.0)
e1	Products and technology	33 (26.2)	e160	Products and technology of land development	27 (21.4)
e540	Transportation services, systems and policies	31 (24.6)	e310	Immediate family	25 (19.8)
e115	Products and technology for personal use in daily living	30 (23.8)	e460	Societal attitudes	24 (19.1)
e315	Extended family	28 (22.2)	e1	Products and technology	22 (17.5)
e340	Personal care providers and personal assistants	27 (21.4)	e340	Personal care providers and personal assistants	22 (17.5)
e555	Associations and organizational services, systems and policies	26 (20.6)	e575	General social support services, systems and policies	20 (15.9)
e590	Labour and employment services, systems and policies	24 (19.1)	e115	Products and technology for personal use in daily living	19 (15.1)
e135	Products and technology for employment	22 (17.5)	e315	Extended family	19 (15.1)
e125	Products and technology for communication	21 (16.7)			
e140	Products and technology for culture, recreation and sport	20 (15.9)			
e160	Products and technology of land development	20 (15.9)			
e575	General social support services, systems and policies	20 (15.9)			

Table V. Distribution of answers by professional background and by country income and odds ratios (OR) for the differences between background and country income, for the most frequently reported International Classification of Functioning, Disability and Health (ICF) categories that were reported by ≥ 50 experts

		Professional background[a]			Country income		
ICF code	ICF category description	Physician *n* (%) (*n* = 66)	Therapist *n* (%) (*n* = 49)	Physician (vs therapist) OR (95% CI); *p*-value	Experts from low- and middle-income countries *n* (%) (*n* = 29)	Experts from high-income countries *n* (%) (*n* = 96)	Low- and middle-income countries (vs high-income countries) OR (95% CI); *p*-value
b	***Body functions***						
b117	Intellectual functions	34 (51.5)	23 (46.9)	1.3 (0.6–2.9); 0.46	16 (55.2)	45 (46.9)	1.7 (0.7–4.1); 0.24
b130	Energy and drive functions	25 (37.9)	22 (44.9)	0.8 (0.4–1.6); 0.48	12 (41.4)	42 (43.8)	1.0 (0.4–2.4); 0.96
b152	Emotional functions	29 (43.9)	19 (38.8)	1.3 (0.6–2.7); 0.56	10 (34.5)	44 (45.8)	0.6 (0.3–1.6); 0.32
b280	Sensation of pain	43 (65.2)	27 (55.1)	1.8 (0.8–4.0); 0.17	10 (34.5)	68 (70.8)	0.2 (0.1–0.6); 0.0015[b]
b710	Mobility of joint functions	27 (40.9)	26 (53.1)	0.6 (0.3–1.3); 0.19	13 (44.8)	43 (44.8)	1.0 (0.4–2.3); 0.93
b735	Muscle tone functions	40 (60.6)	27 (55.1)	1.4 (0.7–3.1); 0.37	15 (51.7)	56 (58.3)	0.9 (0.4–2.1); 0.79
s	***Body structures***						
s110	Structure of brain	45 (68.2)	28 (57.1)	1.6 (0.8–3.6); 0.22	21 (72.4)	55 (57.3)	1.9 (0.7–4.8); 0.19
s730	Structure of upper extremity	31 (47.0)	24 (49.0)	0.9 (0.4–1.9); 0.76	17 (58.6)	41 (42.7)	1.8 (0.8–4.2); 0.18
s750	Structure of lower extremity	40 (60.6)	26 (53.1)	1.3 (0.6–2.8); 0.50	18 (62.1)	54 (56.3)	1.2 (0.5–2.8); 0.71
s760	Structure of trunk	35 (53.0)	20 (40.8)	1.6 (0.7–3.4); 0.24	13 (44.8)	47 (49.0)	0.8 (0.3–1.8); 0.54
d	**Activities and participation**						
d850	Remunerative employment	32 (48.5)	23 (46.9)	1.1 (0.5–2.4); 0.75	10 (34.5)	50 (52.1)	0.5 (0.2–1.2); 0.13
d855	Non-remunerative employment	32 (48.5)	20 (40.8)	1.4 (0.7–3.1); 0.36	9 (31.0)	48 (50.0)	0.5 (0.2–1.1); 0.08
e	***Environmental factors***						
e120	Products and technology for personal indoor and outdoor mobility and transportation	33 (50.0)	36 (73.5)	0.4 (0.2–0.8); 0.02	17 (58.6)	56 (58.3)	1.1 (0.5–2.7); 0.84
e150	Design, construction and building products and technology of buildings for public use	48 (72.7)	41 (83.7)	0.6 (0.2–1.4); 0.22	21 (72.4)	75 (78.1)	0.8 (0.3–2.2); 0.70
e155	Design, construction and building products and technology of buildings for private use	42 (63.6)	35 (71.4)	0.8 (0.3–1.7); 0.51	20 (69.0)	63 (65.6)	1.4 (0.6–3.5); 0.48
e310	Immediate family	38 (57.6)	25 (51.0)	1.2 (0.6–2.6); 0.64	20 (69.0)	49 (51.0)	1.9 (0.8–4.8); 0.16
e315	Extended family	34 (51.5)	19 (38.8)	1.6 (0.8–3.5); 0.22	18 (62.1)	41 (42.7)	2.2 (0.9–5.2); 0.09
e340	Personal care providers and personal assistants	24 (36.4)	22 (44.9)	0.7 (0.3–1.5); 0.33	9 (31.0)	42 (43.8)	0.6 (0.2–1.4); 0.20
e540	Transportation services, systems and policies	28 (42.4)	25 (51.0)	0.8 (0.4–1.6); 0.45	12 (41.4)	45 (46.9)	0.9 (0.4–2.1); 0.77
e580	Health services, systems and policies	38 (57.6)	20 (40.8)	2.2 (1.0–4.7); 0.05	12 (41.4)	53 (55.2)	0.6 (0.3–1.5); 0.30

[a]The researcher group was excluded from the analysis due to their small number.
[b]Significant difference, *p*-value < 0.0025 (with Bonferroni correction).

rents or needed support from their family. The experts also regularly commented on "Services, systems and policies", of which health services were the most often indicated, showing the awareness of the experts of the need to continue healthcare services for persons with CP during their transition to adulthood and thereafter (21, 25, 26). Notably, the experts considered most *Environmental factors* as both supportive and hindering factors for adults with CP, except for "Societal attitudes", which was indicated only as a hindering factor. According to the experts, stigmatization and discrimination can impede social engagement in adults with CP, and this may suggest that society should promote positive attitudes towards adults with CP. Finally, the experts identified several *Personal factors* of importance for adults with CP, but only with low frequencies in this survey, perhaps because they lack a precise idea of which *Personal factors* were specifically relevant for adults with CP.

When comparing the categories addressed between professional backgrounds, no differences were found between physicians and therapists; both groups gave similar response patterns. However, potential differences may have been missed due to the small size of the subsamples. Also, there were no differences in response patterns between experts from high-income countries and low- and middle-income countries, except that the latter countries less frequently reported on "pain". This can be explained by noting that health professionals in limited-resource countries often have to prioritize other important issues, such as life-threatening conditions, over that of pain management (27). Moreover, staff shortages, e.g. not having experts in specialized fields, such as a pain physician, is a huge problem in developing countries, which may have decreased these experts' attention to pain (28).

We found a large number of categories addressing *Environmental factors* compared with a recent systematic literature review on outcomes in adults with CP (12). The experts in our survey were notably concerned about person-environment interactions, whereas only

a few published studies have explored these areas; revealing a gap in the scientific literature. The present expert survey also included responses from many experts in low- and middle-income countries, while most studies in the systematic review were conducted in high-income countries. Thus, we believe this study adds a valuable worldwide perspective on relevant categories for developing an ICF Core Set for adults with CP.

These results are in line with the international expert survey on children with CP (13), except for different highlights in *Activities and participation*. While "school education" was a common issue for children with CP, "employment" and "intimate relationship" were more common in adults with CP. This is in line with changing life situations throughout the lifespan. Thus, the importance of specific life areas may shift with age. Emerging adults with CP may need support from people in their environment and professionals to achieve new personal goals and optimal levels of functioning in adulthood (29). For *Environmental factors*, "family" is the most important factor in the ICF Core Set for children with CP, and also appears to be important for adults with CP. However, in order to live independently in the modern world, "products and technology" are more relevant for adults with CP than for children. These differences show that relevant aspects of functioning and environments are different between adults and children with CP.

Although a sample of 126 experts is a firm base to estimate relevant aspects of functioning and environmental factors for adults with CP, the number of participants in some regions was quite low; for example, in the African region. In addition, it was difficult to reach some disability and professional organizations in these regions. There is no culture or infrastructure of professionals and patient organizations in low- and middle-income countries to carry out collaborative surveys into the health problems of their patient populations (30). In addition, only a small number of healthcare workers and researchers in these regions probably had dedicated working experience with adults with CP. Moreover, the vast majority of physicians and therapists who responded to the survey were rehabilitation physicians and physical therapists, whereas only a small number of experts in other subspecialties participated. This might be a result of the method of sampling (31). On the other hand, it is known that, after leaving paediatric care, people with CP receive most of their care from rehabilitation physicians and physical therapists (32). Focusing on mobility and movement-related function can be understood from the definition of CP as a disorder of movement and posture, although additional impairments are often presented. In addition, the English language might have been a limitation for experts from some regions, such as those from the Eastern Mediterranean region. Furthermore, some parts of the answers were too general or broad to be linked to second-level categories. We adapted to this by allowing first-level categories to be included in the responses.

In conclusion, this study surveyed the ICF categories that are important for adults with CP from experts' perspectives worldwide. The experts identified a wide diversity of ICF categories and, overall, highlighted the importance of person-environment interactions, noting in particular pain, employment, and accessible design of buildings. Together with all preparatory studies, the present results will help to reach a consensus on an ICF Core Set for adults with CP.

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