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ORIGINAL CONTRIBUTION

An international clinical study of ability and disability in ADHD using the WHO-ICF framework

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Abstract
This is the fourth and final study designed to develop International Classification of Functioning, Disability and Health (ICF, and children and youth version, ICF-CY) core sets for attention-deficit hyperactivity disorder (ADHD). To investigate aspects of functioning and environment of individuals with ADHD as documented by the ICF-CY in clinical practice settings. An international cross-sectional multi-centre study was applied, involving nine units from eight countries: Denmark, Germany, India, Italy, Portugal, Saudi Arabia, Sweden and Taiwan. Clinicians and clinical researchers rated the functioning level of 112 children, adolescents and adults with ADHD using the extended ICF-CY checklist version 2.1a. The ratings were based on a variety of information sources, such as medical records, medical history, clinical observations, clinical questionnaires, psychometric tests and structured interviews with participants and family members. In total, 113 ICF-CY categories were identified, of which 50 were related to the activities and participation, 33 to environmental factors and 30 to body functions. The clinical study also yielded strengths related to ADHD, which included temperament and personality functions and recreation and leisure. The study findings endorse the complex nature of ADHD, as evidenced by the many functional and contextual domains impacted in ADHD. ICF-CY based tools can serve as foundation for capturing various functional profiles and environmental facilitators and barriers. The international nature of the ICF-CY makes it possible to develop user-friendly tools that can be applied globally and in multiple settings, ranging from clinical services and policy-making to education and research.

Keywords ADHD · Neurodevelopmental disorder · Functioning · Assessment · Psychiatry · ICD · DSM · Quality of life · Clinical study

Background

Attention-deficit hyperactivity disorder (ADHD) is a neurodevelopmental condition behaviourally defined by patterns of persistent age inappropriate inattention, hyperactivity and impulsivity [1], affecting 3–7% of children and adults worldwide [2–5]. ADHD is also characterized by cognitive difficulties [6], and impacts significantly on management of daily routines [7], school [8], work [9] and social relationships [10]. In addition, ADHD is associated with an increased risk for other neurodevelopmental and psychiatric conditions [11, 12], poorer quality of life [13], and premature mortality [14]. Despite these negative outcomes in individual functioning, reports also suggest that there may be specific strengths related to ADHD, such as creativity and hyperfocusing [15, 16], although these have not been documented consistently by research [17, 18]. Other studies have found certain personality features, such as inspiration and feelings of togetherness, to facilitate coping strategies in individuals with ADHD [19]. Supportive factors in the environment, such as special education programs and pharmacological treatments, have been shown to reduce challenges in ADHD [20, 21], while lack of support and negative attitudes from family members often result in increased behavioural problems [22]. To standardize the assessment of functioning

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and environmental influences in individual cases of ADHD in clinical, research and educational settings, it would be helpful to have internationally, accepted classification tools available. The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) can serve as foundation for developing such tools [23]. Officially endorsed by the WHO in 2001, the ICF aims to provide a comprehensive, universally accepted framework to describe health-related functioning in different conditions and condition groups. In 2007, a Child and Youth version of the ICF, the ICF-CY, was specifically designed to capture functional aspects in developing individuals by adding and expanding on the descriptions of already existing ICF-categories [24].

The ICF-CY is based on a bio-psycho-social model of functioning, which conceptualizes functioning and disability as the outcome of complex interactions between health conditions and contextual factors (environmental and personal factors). The ICF-CY provides detailed classifications of the components of body functions (i.e., physiological functions of body systems), body structures (i.e., anatomical parts of the body), activities (i.e., execution of tasks), participation (i.e., involvement in life situations), and environmental factors (i.e., physical, social and attitudinal environment). The components are divided into different chapters, which provide a general overview of the areas of functioning and environment that are covered by the nomenclature. For each of these chapters, aspects of functioning and environment can be described in three levels of increasing detail, as demonstrated by the following activities and participation component example:

- Level 1 chapter: d7 Interpersonal interactions and relationships
- Level 2 category: d710 Basic interpersonal interactions
- Level 3 category: d7104 Social cues in relationships
- Level 4 category: d71040 Initiating social interactions

The ICF-CY framework also includes personal factors that are inherent to the individual, but not part of the individual's primary health condition, such as race, gender, age, educational level and coping styles. Personal factors are not specifically coded in the ICF-CY, partly because of the large social and cultural variability associated with them [23, 24], but also due to a lack of consensus on how to classify them and what kind of factors that would be appropriate to be included in the nomenclature [25]. However, there have been attempts to classify personal factors into categorical codes. For example, Grotkamp et al. [26] proposed to structure 72 personal factors into 6 different chapters. The ICF-CY, which includes all ICF-categories, plus additional ones for children and youth, consists of 1685 categories (531 body functions; 329 body structures; 552 activities and participation categories; and 273 environmental factors). The classification provides a comprehensive, common and universal language for clinicians and researchers to document and measure functional health across the lifespan for diagnostic, treatment and reimbursement purposes [27, 28]. However, using all the categories of the ICF-CY to describe an individual with a specific diagnosis is time-consuming and essentially inappropriate, as many categories may not apply to a person with a certain condition. To address this issue, the development of ICF Core Sets was initiated by providing shortlists of categories that are relevant to specific health conditions and health-related settings. The development of Core Sets comprises four preparatory studies, namely a clinical study (current study, "clinical perspective"), a scoping literature review ("research perspective"), an expert survey ("expert perspective") and a qualitative study ("client and social environment perspective"). This development process follows a rigorous scientific procedure that involves a wide range of professionals and stakeholders across all WHO-regions [29]. The present study is therefore part of a larger systematic effort that will subsequently lead to the development of standardized ICF Core Sets for ADHD. As part of this project, ICF Core Sets are also being developed for Autism Spectrum Disorder (ASD), with the results reported in separate publications [30–33].

The objective of this study was to capture functional and contextual features in individuals with ADHD as assessed by the ICF-CY in a clinical practice setting. For this purpose, an international cross-sectional multi-centre study was conducted, involving clinicians and clinical researchers evaluating the functional level of children, adolescents and adults with ADHD, as well as environmental barriers and facilitators and ADHD-related strengths.

Methods

Design and procedure

The study was approved by the regional ethics review board in Stockholm and by local ethics review boards at each of the participating sites. Written consent was obtained from each participant and/or parent or legal guardian prior to study participation, depending on age and communication skills. The consent form assured voluntarily study participation and confidentiality. An international cross-sectional, multi-centre design, as recommended by the WHO and ICF Research Branch, was chosen for this study, and involved nine clinical units from eight countries across four WHO-regions: Denmark (Europe), Germany (two sites) (Europe), India (South-East Asia), Italy (Europe), Portugal (Europe), Saudi Arabia (Eastern Mediterranean), Sweden (Europe) and Taiwan (Western Pacific). This broad composition of countries

was deliberately chosen, given that cross-cultural effects have been found to influence attitudes, assessment and treatment of ADHD [34]. Participating sites were specialized in the management of neurodevelopmental disorders. The ICF-CY rating was made based on information from medical records and history taking, clinical questionnaires (e.g., Conners Rating Scale, Behavior Rating Inventory of Executive Function), psychometric test scores (e.g., Wechsler Intelligence Scale for Children and Adults, Conners Continuous Performance Test), clinical observations and interviews with the participant and/or caregivers depending on age and developmental level of the rated case. In case there was any discordant information from the different sources, the investigators were asked to rely on their clinical judgment. Each clinical investigator checked available medical information for each participant prior to the interviews and extracted information on socio-demography, co-morbidity and ADHD-related functioning aspects. The investigators then proceeded to interview the participant and/or caregivers to rate the remaining ICF-CY categories of the checklist. The interviews lasted between 25 and 120 min. Telephone interviews were occasionally used as an option to accommodate logistical challenges, but also to comply with some participants' wishes to be interviewed via the phone.

Participants

In total, $N = 119$ participants fulfilled criteria for participation and consented to take part in the study between March and August 2016. Inclusion criteria were having a primary clinical diagnosis of ADHD (along with any given common co-morbidity, if applicable) according to local or national guidelines and the diagnostic criteria of the ICD-10, DSM-IV/TR or DSM-5 and/or receiving treatment for ADHD. Participants were excluded from the study if the caregiver or the individual diagnosed with ADHD could not communicate in their country's native language. Recruitment of participants was mainly conducted at the respective clinical unit led by the clinical investigators in charge. Most of the adults ($n = 39$) were, however, recruited via local and national interest organizations for ADHD. For most of these adult cases, access to medical records was limited and the rating of functioning level was based primarily on interview information. Following previous ICF clinical studies for Core Sets development [35, 36], this study aimed to enroll at least 100 participants.

WHO-ICF-CY checklist

The WHO-ICF Checklist 2.1a [37] is a tool to elicit and record information on individual health-related functioning using selected categories from the ICF-CY. The checklist comprises 123 second-level ICF-CY categories across all four ICF-CY components: 31 body functions, 12 body structures, 48 activities and participation, and 32 environmental factors. Moreover, the checklist also includes diagnostic information, which enables users to explore the relationship between a health condition and associated functioning problems. ICF qualifiers are usually applied to rate the categories in the checklist. The qualifiers represent a 5-point scale that defines severity of functional impact as how often a specific problem is present in an individual's daily life. Previous studies have investigated the validity of the ICF checklist [38–40]. The feasibility of the checklist has been shown in patients diagnosed with different kinds of conditions, including psychiatric ones, such as depression [38]. For the current study, an extended version of the WHO-ICF Checklist version 2.1a was used to rate functional abilities and disabilities in individuals with ADHD [see Supplementary Material]. The specificity of the checklist content was increased by including additional 30 ICF-CY categories (12 body functions; 14 activities and participation; 4 environmental factors) that were found to be important in ADHD based on the previous three preparatory studies; a comprehensive scoping review [41], an expert survey [15] and a qualitative study [16]. The checklist was divided into four parts. Part 1 listed the inclusion criteria of the study; part 2 captured the socio-demographics of the participant; part 3 included ratings of 153 ICF-CY categories; part 4 explored personal factors. An adapted version of the Numeric Rating Scale (NRS) was used to rate each ICF-CY category in the checklist. The NRS [42], which has been validated and commonly used to assess pain intensity [42], utilizes an 11-point scale, with 0 representing "no", 1–3 "mild", 4–6 "moderate" and 7–10 "severe symptoms/impairments". For this study, clinical investigators at each respective study site rated functional abilities and disabilities according to the NRS, following the same metrics as stated above, i.e., "0" representing no functional disability and "7–10" severe functional disability. The primary reason for using the NRS in this study was because of its relative simplicity and ease of administration and scoring [43]. While the ICF qualifiers define impact of functional impairment as how often a specific problem is experienced in daily life, the NRS does not offer a specific definition on how to assess functional impairment. Instead, it enables users to explore other factors that may impact the individual's functional level, such as degree and duration of impairment. In addition, ICF qualifiers have also been reported to be difficult to interpret by specific stakeholders [44]. The categories in the environmental factors were also rated according to the NRS, but with 0 representing "no barrier or facilitator", + 10 "complete facilitator" and − 10 "complete barrier". For all the components in the checklist, additional scoring options of "Not applicable" and "Not specified" were added. "Not applicable" was used if a specific ICF-CY category was not applicable to the individual

(e.g., sexual functions in children), while the "Not specified" option was applied if there was not sufficient information to rate the specific category. An option to capture potential strengths was also included in the checklist and these were rated according to the NRS. A strength was defined as a specific ability that an individual with ADHD is better at compared to the average population. Information from the assessments that indicated potential strengths (e.g., above-average test scores or notes from clinical observations) was used for this purpose. To minimize the possibility of over or underestimation of disabilities or strengths, the investigators were instructed to ask participants for examples and clarifications. Functioning aspects that were not included in the checklist, but deemed important to ADHD, were also documented and rated according to the NRS. The selected 153 second-level ICF-CY categories were distributed across all four ICF-CY components in the checklist as follows: 62 body functions, 43 activities and participation categories, 36 environmental factors and 12 body structures. The checklist also included an empty page for investigators to document any personal factors that were considered (either by the diagnosed individual or caregiver) to impact daily life functioning of ADHD. The personal factors, which were not rated, could either support or hamper the individual's functional level. These were documented descriptively in the interviews with the participant and/or caregiver.

Data analysis

Any ICF-CY category that was rated with "2" or more in at least 10% of the cases was included as candidate category for the core set development. Although a scoring of "1" would be enough to classify a specific aspect of functioning or environmental factor as "mildly impaired/barrier/facilitator", a more conservative cut-off was chosen to avoid margins of error (e.g., a specific challenge might exist in daily life, but not be significantly impairing enough to affect functioning level). The choice of a 10% cut-off was based on results from previous ICF clinical studies [45], and it was also used for ratings indicating strengths. Absolute (n) and relative (%) frequencies of difficulties and strengths are reported. Ratings that indicated "Not applicable" or "Not specified" were excluded from the frequency analyses. The participants' socio-demographic background was summarized using descriptive statistics. Personal factors were linked to second-level categories as classified by Grotkamp et al. [26].

Quality assurance

Prior to study participation, each participating study site was required to take part in a web-based ICF self-learning course (http://icf.ideaday.de/). The course included an introduction to the ICF, its rationale and application areas. The aim of the course was twofold. First, to help the investigators understand the ICF model and classification terms used in the nomenclature. Second, to acquaint the investigators with applying the ICF in practice. The investigators were required to pass all the training modules in the ICF course with 100% accuracy. Once the course was completed, the investigators received examples of questions that they could use for the interviews with the participants. Each second-level ICF-CY category in the checklist was provided with clear definitions and examples, helping the investigators to get familiar with the checklist content. Skype meetings were arranged to discuss specific ICF-CY categories that were unclear. The checklist content was translated into the languages of each participating study site, with the exception of Denmark, which used an English version. The study coordinator (S.M.) had regular contact with the study sites, monitoring their progress and providing material for quality management and comparability (e.g., sending interview experiences from other study sites).

Sample

Of the 119 participants who were eligible for participation, 112 completed the study. Attrition in 7 cases was due to not showing up for assessment ($n = 4$), or subsequently declining to participate in the study ($n = 3$) after initial consent. Table 1 shows the number of participants by country. Table 2 summarizes the socio-demographics of the participants who were included in the final analysis with respect to age, gender, marital status, education background, occupational status and living situation. Combined ADHD was the most frequent subtype ($n = 76$, 68%), followed by the predominantly inattentive subtype ($n = 25$, 22%), predominantly hyperactive-impulsive subtype ($n = 4$, 4%) and unspecified ADHD ($n = 1$, 1%). In six participants (5%), the ADHD subtype had not been specified. The majority of the participants ($n = 62$, 55%) reported having at least one additional diagnosis. The most frequently reported co-morbidities were neurodevelopmental disorders (e.g., ASD, motor tics, communication disorders; $n = 25$, 22%), mood disorders (e.g., depression, anxiety, obsessive

Table 1 Participants by country and WHO-regions

Country	WHO-region	*N* (%)
Sweden	Europe	48 (43)
Taiwan	Western Pacific	24 (21)
Germany (Dresden + Marburg)	Europe	14 (13)
Saudi Arabia	Eastern Mediterranean	9 (8)
Italy	Europe	6 (5)
Portugal	Europe	6 (5)
India	South East Asia	4 (4)
Denmark	Europe	1 (1)

Table 2 Socio-demographic variables of participating children, adolescents and adults with ADHD

Socio-demographic variables	*N* (%)	Gender (female/male) N (%)	Age M (SD) range
Age group			
Children with ADHD (age: 6–12 years)	51 (46)	7/44 (14/86)	9.0 (1.8) 6–12
Adolescents with ADHD (age: 13–17 years)	17 (15)	4/13 (24/76)	14.3 (1.6) 13–17
Adults with ADHD (age: 18+ years)	44 (39)	29/15 (66/34)	37.3 (11.7) 18–61
Marital status			
Single	82 (73)		
Married	13 (12)		
In domestic relationship	6 (5)		
Divorced/separated	3 (3)		
Other marital status[a]	8 (7)		
Education level			
Primary/high school studies	80 (71)		
Higher education (e.g., college or university)	23 (21)		
Vocational education	3 (3)		
Other education level[b]	6 (5)		
Working status			
Student	67 (59)		
Full-time employment	19 (16)		
Combined forms of employment	9 (8)		
Receiving benefit grants	4 (4)		
Part-time employment	3 (3)		
Sick leave	3 (3)		
Unemployment	3 (3)		
Self-employment	2 (2)		
Sickness benefits	1 (1)		
Volunteer work	1 (1)		
Living situation			
Living with parents	65 (59)		
Living with partner	19 (16)		
Living independently	18 (16)		
Other living situation[c]	10 (9%)		

[a]Other marital status includes dating, long-distance relationships, live-apart, etc

[b]Other educational level includes preschool and folk high school

[c]Other living situation includes living with a friend or grandparent, residential care, etc

compulsive disorder, bipolar disorder; $n = 17$, 15%), externalizing behaviour problems (e.g., conduct disorder, oppositional defiant disorder; $n = 10$, 9%) and learning disorders (e.g., dyslexia, dysgraphia, dyscalculia; $n = 7$, 6%).

Results

ICF-CY category ratings

In total, 113 ICF-CY categories were identified that met the 10% cut-off. Data saturation [46] showed that no candidate category would have been lost if only European data would have been included. The categories were distributed across three of the four ICF-CY components: 50 categories from the activities and participation component, 33 environmental factors and 30 body functions. No body structure categories reached the cut-off. Table 3 shows the second-level categories that were captured in the different components, along with their absolute and relative frequencies. Categories in the activities and participation component were spread across all of the nine chapters, i.e., *d1 learning and applying knowledge (k = 12), d5 self-care (k = 7), d7 interpersonal interactions and relationships*

Table 3 Absolute and relative frequencies of identified ICF-CY categories from the activities and participation, environmental factors and body functions components

Second-level category	ICF-CY chapter	*N* (%)
Activities and participation		
d110 Watching	d1 Learning and applying knowledge	16 (14)
d115 Listening	d1 Learning and applying knowledge	29 (25)
d140 Learning to read	d1 Learning and applying knowledge	27 (24)
d145 Learning to write	d1 Learning and applying knowledge	26 (23)
d150 Learning to calculate	d1 Learning and applying knowledge	29 (25)
d160 Focusing attention	d1 Learning and applying knowledge	102 (91)
d161 Directing attention	d1 Learning and applying knowledge	102 (91)
d166 Reading	d1 Learning and applying knowledge	46 (41)
d170 Writing	d1 Learning and applying knowledge	46 (41)
d172 Calculating	d1 Learning and applying knowledge	50 (44)
d175 Solving problems	d1 Learning and applying knowledge	58 (51)
d177 Making decisions	d1 Learning and applying knowledge	59 (52)
d210 Undertaking a single task	d2 General tasks and demands in life	72 (64)
d220 Undertaking multiple tasks	d2 General tasks and demands in life	91 (81)
d230 Carrying out daily routine	d2 General tasks and demands in life	80 (71)
d240 Handling stress and other psychological demands	d2 General tasks and demands in life	74 (66)
d250 Managing one's own behaviour	d2 General tasks and demands in life	77 (68)
d310 Communicating with—receiving—spoken messages	d3 Communication	31 (27)
d315 Communicating with—receiving—nonverbal messages	d3 Communication	32 (28)
d330 speaking	d3 Communication	32 (28)
d335 Producing nonverbal messages	d3 Communication	20 (17)
d350 Conversation	d3 Communication	55 (49)
d440 fine Hand use	d4 Mobility	34 (30)
d446 Fine foot use	d4 Mobility	20 (17)
d470 Using transportation	d4 Mobility	15 (13)
d475 Driving	d4 Mobility	22 (19)
d510 Washing oneself	d5 Self-care	26 (23)
d520 Caring for body parts	d5 Self-care	34 (30)
d530 Toileting	d5 Self-care	20 (17)
d540 Dressing	d5 Self-care	18 (16)
d550 Eating	d5 Self-care	18 (16)
d570 Looking after one's health	d5 Self-care	52 (46)
d571 Looking after one's safety	d5 Self-care	49 (43)
d620 Acquisition of goods and services	d6 Domestic life	35 (31)
d630 Preparing meals	d6 Domestic life	31 (27)
d640 Doing housework	d6 Domestic life	51 (45)
d660 Assisting others	d6 Domestic life	25 (22)
d710 Basic interpersonal interactions	d7 Interpersonal interactions and relationships	54 (48)
d720 Complex interpersonal interactions	d7 Interpersonal interactions and relationships	71 (63)
d730 Relating with strangers	d7 Interpersonal interactions and relationships	23 (20)
d740 Formal relationships	d7 Interpersonal interactions and relationships	37 (33)
d750 Informal social relationships	d7 Interpersonal interactions and relationships	38 (33)
d760 Family relationships	d7 Interpersonal interactions and relationships	44 (39)
d770 Intimate relationships	d7 Interpersonal interactions and relationships	32 (28)
d820 School education	d8 Major life areas	32 (28)
d850 Remunerative employment	d8 Major life areas	21 (18)
d870 Economic self-sufficiency	d8 Major life areas	27 (24)
d880 Engagement in play	d8 Major life areas	17 (15)

Table 3 (continued)

Second-level category	ICF-CY chapter	*N* (%)
d910 Community life	d9 Community, social and civic life	15 (13)
d920 Recreation and leisure	d9 Community, social and civic life	42 (37)
Environmental factors		
e110 Products or substances for personal consumption	e1 Products and technology	72 (64)
e115 Products and technology for personal use in daily living	e1 Products and technology	77 (68)
e120 Products and technology for indoor and outdoor mobility and transportation	e1 Products and technology	29 (25)
e125 Products and technology for communication	e1 Products and technology	58 (51)
e130 Products and technology for education	e1 Products and technology	28 (25)
e165 Assets	e1 Products and technology	23 (20)
e225 Climate	e2 Natural environment and human-made changes to environment	35 (31)
e240 Light	e2 Natural environment and human-made changes to environment	42 (37)
e250 Sound	e2 Natural environment and human-made changes to environment	51 (45)
e310 Immediate family	e3 Support and relationships	95 (84)
e315 Extended family	e3 Support and relationships	38 (33)
e320 Friends	e3 Support and relationships	65 (58)
e325 Acquaintances, peers, colleagues, neighbours and community members	e3 Support and relationships	38 (33)
e330 People in positions of authority	e3 Support and relationships	59 (52)
e340 Personal care providers and personal assistants	e3 Support and relationships	19 (16)
e355 Health professionals	e3 Support and relationships	81 (72)
e360 Other professionals	e3 Support and relationships	40 (35)
e410 Individual attitudes of immediate family members	e4 Attitudes	88 (78)
e420 Individual attitudes of friends	e4 Attitudes	56 (50)
e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	e4 Attitudes	36 (32)
e440 Individual attitudes of personal care providers and personal assistants	e4 Attitudes	15 (13)
e450 Individual attitudes of health professionals	E4 Attitudes	71 (63)
e455 Individual attitudes of other professionals	e4 Attitudes	29 (25)
e460 Societal attitudes	E4 Attitudes	53 (47)
e465 Social norms, practices and ideologies	e4 Attitudes	51 (45)
e535 Communication services, systems and policies	e5 Services, systems and policies	40 (35)
e540 Transportation services, systems and policies	e5 Services, systems and policies	13 (11)
e550 Legal services, systems and policies	e5 Services, systems and policies	19 (16)
e570 Social security services, systems and policies	e5 Services, systems and policies	28 (25)
e575 General social support services, systems and policies	e5 Services, systems and policies	18 (16)
e580 Health services, systems and policies	e5 Services, systems and policies	77 (68)
e585 Education and training services, systems and policies	e5 Services, systems and policies	33 (29)
e590 Labour and employment services, systems and policies	e5 Services, systems and policies	25 (22)
Body functions		
b114 Orientation functions	b1 Mental functions	32 (28)
b122 Global psychosocial functions	b1 Mental functions	53 (47)
b125 Dispositions and intra-personal functions	b1 Mental functions	67 (59)
b126 Temperament and personality functions	b1 Mental functions	61 (54)
b130 Energy and drive functions	b1 Mental functions	64 (57)
b134 Sleep functions	b1 Mental functions	49 (43)
b140 Attention functions	b1 Mental functions	108 (96)
b144 Memory functions	b1 Mental functions	71 (63)
b147 Psychomotor functions	b1 Mental functions	63 (56)

Table 3 (continued)

Second-level category	ICF-CY chapter	*N* (%)
b152 Emotional functions	b1 Mental functions	75 (66)
b156 Perceptual functions	b1 Mental functions	24 (21)
b160 Thought functions	b1 Mental functions	50 (44)
b163 Basic cognitive functions	b1 Mental functions	30 (26)
b164 Higher-level cognitive functions	b1 Mental functions	79 (70)
b167 Mental functions of language	b1 Mental functions	34 (30)
b180 Experience of self and time functions	b1 Mental functions	46 (41)
b230 Hearing functions	b2 Sensory functions and pain	12 (10)
b235 Vestibular functions	b2 Sensory functions and pain	21 (18)
b265 Touch function	b2 Sensory functions and pain	27 (24)
b280 Sensation of pain	b2 Sensory functions and pain	34 (30)
b330 Fluency and rhythm of speech functions	b3 Voice and speech functions	27 (24)
b440 Respiration functions	b4 FUNCTIONS of the cardiovascular, hematological, immunological and respiratory systems	12 (10)
b525 Defecation functions	b5 Functions of the digestive, metabolic and endocrine systems	13 (11)
b530 Weight maintenance functions	b5 Functions of the digestive, metabolic and endocrine systems	29 (25)
b535 Sensations associated with the digestive system	b5 Functions of the digestive, metabolic and endocrine systems	20 (17)
b640 Sexual functions	b6 Genitourinary and reproductive functions	18 (16)
b710 Mobility of joint functions	b7 Neuromusculoskeletal and movement-related functions	14 (12)
b735 Muscle tone functions	b7 Neuromusculoskeletal and movement-related functions	27 (24)
b760 Control of voluntary movement functions	b7 Neuromusculoskeletal and movement-related functions	33 (29)
b765 Involuntary movement functions	b7 Neuromusculoskeletal and movement-related functions	17 (15)

(k = 7), d2 general tasks and demands (k = 5), d3 communication (k = 5), d4 mobility (k = 4), d6 domestic life (k = 4), d8 major life areas (k = 4) and *d9 community, social and civic life (k = 2).* The three most identified second-level categories in the activities and participation component were *d160 focusing attention (n = 102, 91%), d161 directing attention (n = 102, 91%)* and *d220 undertaking multiple tasks (n = 91, 81%).*

Environmental factors were identified in all five chapters, i.e., *e3 support and relationships (k = 8), e4 attitudes (k = 8), e5 services, systems and policies (k = 8), e1 products and technology (k = 6)* and *e2 natural environment and human-made changes to environment (k = 3).* The three most identified second-level categories included *e310 immediate family (n = 95, 84%), e410 individual attitudes of immediate family members (n = 88, 78%)* and *e355 health professionals (n = 81, 72%).*

Of the eight chapters included in the body functions component, six were represented in this study. A large majority of the categories came from *b1 mental functions (k = 16).* Other categories were from *b2 sensory functions and pain (k = 4), b7 neuromusculoskeletal and movement-related functions (k = 4), b5 functions of the digestive, metabolic and endocrine systems (k = 3), b3 voice and speech functions (k = 1), b4 functions of the cardiovascular, haematological, immunological and respiratory systems (k = 1)* and *b6 genitourinary and reproductive functions (k = 1).* The three most identified second-level categories in the body functions component were all from chapter b1 mental functions, namely *b140 attention functions (n = 108, 96%), b164 higher-level cognitive functions (n = 79, 70%)* and *b152 emotional functions (n = 75, 66%).*

ADHD-related strengths

Table 4 presents the frequencies of second-level ICF-CY categories that were rated as strengths in individuals with ADHD. Of the 22 ICF-CY categories that were identified as strengths, 19 were from chapters in the activities and participation component: *d7 interpersonal interactions and relationships (k = 4), d1 learning and applying knowledge (k = 3), d4 mobility (k = 3), d6 domestic life (k = 3), d9 community, social and civic life (k = 3), d8 major life areas (k = 2)* and *d3 communication (k = 1).* The remaining categories originated from *b1 mental functions chapter* in the body functions component. The three most identified strengths were *b126 temperament and personality functions (n = 27, 24%), d920 recreation and leisure (n = 21, 18%)* and *b125 dispositions and intra-personal functions (n = 20, 17%).*

Table 4 Absolute and relative frequencies of ICF-CY categories related to ADHD-strengths

Second-level category	ICF-CY chapter	*N* (%)
b126 Temperament and personality functions	b1 Mental functions	27 (24)
d920 Recreation and leisure	d9 Community, social and civic life	21 (18)
b125 Dispositions and intra-personal functions	b1 Mental functions	20 (17)
d750 Informal social relationships	d7 Interpersonal interactions and relationships	20 (17)
d660 Assisting others	d6 Domestic life	19 (16)
d760 Family relationships	d7 Interpersonal interactions and relationships	18 (16)
d175 Solving problems	d1 Learning and applying knowledge	16 (14)
d630 Preparing meals	d6 Domestic life	15 (13)
b144 Memory functions	b1 Mental functions	14 (12)
d110 Watching	d1 Learning and applying knowledge	14 (12)
d335 Producing nonverbal messages	d3 Communication	14 (12)
d740 Formal relationships	d7 Interpersonal interactions and relationships	14 (12)
d880 Engagement in play	d8 Major life areas	14 (12)
d950 Political life and citizenship	d9 Community, social and civic life	14 (12)
d161 Directing attention	d1 Learning and applying knowledge	13 (11)
d450 Walking	d4 Mobility	13 (11)
d455 Moving around	d4 Mobility	13 (11)
d475 Driving	d4 Mobility	13 (11)
d640 Doing housework	d6 Domestic life	13 (11)
d930 Religion and spirituality	d9 Community, social and civic life	13 (11)
d730 Relating with strangers	d7 Interpersonal interactions and relationships	12 (10)
d810 Informal education	d8 Major life areas	12 (10)

Personal factors

Table 5 summarizes the personal factor categories covered in this study. In total, 212 meaningful concepts were identified and linked to 30 second-level personal factors. The categories represented five of six chapters, namely i4 attitudes, basic skills and behaviour patterns ($k = 12$), i3 mental factors ($k = 9$), i5 life situation and socioeconomic/sociocultural factors ($k = 7$), i1 general personal characteristics ($k = 1$) and i6 other health factors ($k = 1$). Personal factors can either positively or negatively impact the living experiences of ADHD. The five most recurring codes consisted of i436 empowerment (i.e., self-motivation, endurance), i330 affability (i.e., willingness to cooperate, altruism), i350 intelligence-related factors (i.e., comprehension, IQ), i433 methodical skills (i.e., creativity, coping-skills), and i525 financial situation (i.e., gainful employment, property holdings).

Discussion

This international cross-sectional clinical study is the final preparatory study to develop ICF Core Sets for ADHD. We recruited individuals with ADHD from nine clinical units across eight countries and four WHO-regions. As expected, the most commonly identified difficulties in the activities and participation component were related to tasks and actions that required attention. Other commonly identified restrictions included undertaking multiple tasks (i.e., initiating and completing multiple tasks in sequence or simultaneously) and carrying out daily routines (i.e., managing time, planning activities). Various aspects of learning and applying knowledge (i.e., making decisions, solving problems) were also recurrently identified as challenges. The main environmental factors varied from attitudes and support from immediate family members or health professionals (i.e., doctors, psychologists) to usage of products and technology in daily living (i.e., cell-phones, timers). Not surprisingly, many mental functions were covered in this study. Other body functions identified were gastro-intestinal issues, hypersensitivity problems and motor coordination difficulties. Strengths associated with ADHD included different temperament and personality functions (i.e., agreeableness, openness to experience, optimism), participation in recreation and leisure activities (i.e., socializing, hobbies), and dispositions and intra-personal functions (i.e., persistence, activity level). Personal factors were broadly mentioned in this study, ranging from creativity, affability and empowerment to financial situation, social skills and prior experiences of traumas or injuries.

Table 5 Personal factors that either hamper or support ADHD functioning (as classified by Grotkamp et al. 2012)

Second-level category	Chapter	*N*
i120 Sex	i1 General personal characteristics	1
i310 Extraversion	i3 Mental factors	5
i315 Factors of emotionality	i3 Mental factors	6
i320 Reliability	i3 Mental factors	5
i325 Openness to new experiences	i3 Mental factors	6
i330 Affability	i3 Mental factors	7
i335 Self-confidence	i3 Mental factors	4
i340 Optimism	i3 Mental factors	5
i350 Intelligence-related factors	i3 Mental factors	7
i355 Cognitive factors	i3 Mental factors	3
i410 World view	i4 Attitudes	2
i416 Attitude toward health and disease	i4 Attitudes	3
i419 Attitude toward intervention and health-related assistance	i4 Attitudes	1
i428 Attitude toward help	i4 Attitudes	4
i430 Social skills	i4 Attitudes	6
i433 Methodical skills	i4 Attitudes	7
i436 Empowerment	i4 Attitudes	18
i439 Proaction	i4 Attitudes	5
i442 Media skills	i4 Attitudes	1
i453 Habitual use of stimulants	i4 Attitudes	3
i456 Exercise habits	i4 Attitudes	2
i459 Relaxation habits	i4 Attitudes	1
i510 Living arrangements	i5 Life situation and socioeconomic/sociocultural factors	5
i515 Accommodation arrangements	i5 Life situation and socioeconomic/sociocultural factors	1
i520 Employment situation	i5 Life situation and socioeconomic/sociocultural factors	2
i525 Financial situation	i5 Life situation and socioeconomic/sociocultural factors	7
i530 Socioeconomic status	i5 Life situation and socioeconomic/sociocultural factors	2
i540 Belonging to groups in society	i5 Life situation and socioeconomic/sociocultural factors	2
i550 Educational status	i5 Life situation and socioeconomic/sociocultural factors	2
i610 Prior diseases, health impairments, injuries or traumas	i5 Life situation and socioeconomic/sociocultural factors	4

Identified ICF-CY categories

This study yielded a large number and variety of ICF-CY categories across three of four components and twenty ICF-CY chapters. Besides neuropsychological functions, the impact of ADHD also broadened out to include other areas of body functions, such as sensory, motor and gastro-intestinal issues. The association between ADHD and motor coordination difficulties has previously been established in research [47]. The same is true for gastro-intestinal problems [48] and hypersensitivity to sensory stimuli [49]. Although the current research literature and expert opinions stress the importance of treating co-morbid conditions in the ADHD population, physical problems are still rarely targeted or appropriately addressed by service providers [50]. The bio-psycho-social model of the ICF-CY can bridge this gap by offering a comprehensive framework that enables diverse range of functioning profiles to be captured and measured for diagnostic and treatment purposes. Treating co-morbid somatic conditions in ADHD can yield successful clinical outcomes, as it may help individuals reduce self-blame and facilitate the process of self-control [51]. The clinical heterogeneity of ADHD is further attested by the fact that categories were identified from all nine chapters in the activities and participation component. Consistent with previous research and the operationalization of ADHD, this study supported difficulties in general demands of life, social relationships and school [7–10, 52]. These challenges could be described here in more detail through the use of the IC-CY standardized system. This standardized system can serve to facilitate multidisciplinary assessments by enabling more efficient communication between different professionals and organizations. Corroborating our own research [15, 16, 41], this study identified relevant environmental factors across different chapters of the ICF-CY, highlighting

the importance of taking into account all types of facilitators and barriers in the environment when conducting functional assessments related to ADHD. One of the most referenced chapters in the environmental factors component was attitudes, which might be explained by the fact that ADHD is still not fully accepted as a bona-fide medical condition among some community members [53, 54]. In fact, previous research has shown that individuals with ADHD encounter negative experiences accessing care due to skeptical attitudes towards ADHD by health professionals and a lack of expertise in the area [55]. Another environmental chapter that was frequently covered in this study was support and relationships, which contains information on people or animals that provide practical, physical or emotional support to individuals. Given the large number of countries that were included in this study, it is not surprising that different types of supportive individuals were identified. Environmental facilitators and barriers can vary substantially depending on region and culture [34]. For example, a lack of support from extended family members might not have too great of an impact on functioning in highly individualized societies compared to those based on a more collectivistic culture, where large groups of families tend to live close to each other. Broad variation of services was also captured in this study, ranging from health care providers and special education interventions to labour employment and social security programs. Despite the extensive impact of ADHD on individual functioning, there is still a growing demand for services that can be offered in addition to pharmacological treatments [56]. The need for non-pharmacological interventions can be explained by numerous reasons. First, although pharmacological treatments are efficacious and widely used [21], its long-term effectiveness remains to be established [57]. Second, non-adherence to medication has been observed in some individuals with ADHD who experience adverse side effects, including mood instability, heart palpation, nausea and anxiety [58]. Third, some parents may have reservations about psychopharmacological treatments [59]. Our results underpin the importance of delivering adequate services in multiple clinical, educational and community settings to optimize ADHD outcome in individuals with ADHD. Interestingly, this study also yielded categories related to the immediate physical individual environment, such as light and sound. These physical factors in the environment seem more essential in clinical settings to individuals with ADHD and their caregivers compared to existing research literature [41] and expert opinions [15]. No body structures were identified in this study when using clinical records and the ICF-CY Checklist for their assessment. Nevertheless, detailed physical or neurological examinations were not conducted, as they are currently not an integral international standard of diagnosing ADHD.

ADHD-related strengths

This is to our knowledge the first international clinical study that investigated strengths in individuals with ADHD using the ICF-CY framework. The strengths captured were quite broad and variable, reflecting the heterogeneity of ADHD presentation. Some participants mentioned that their ADHD made it easier for them to be open to new experiences and try new things in life. Others emphasized the role that ADHD played in taking initiative to create new hobbies or participate in social events. Contrary to the expert survey and qualitative study [15, 16], this study identified new aspects of strengths in ADHD, such as making friends and having good relationships with family members. Some participants mentioned that they were able to form meaningful social relationships with their loved ones after many years of practice and learning, while others felt that ADHD made it automatically easier for them to approach people and initiate meaningful interactions that later led to deeper social bonds. The strengths identified in the current study can, in combination with the results from the expert survey [15] and qualitative study [16], lead to future novel hypotheses for research, where the topic of ADHD-related strengths can be more comprehensively explored. Focusing on strengths in ADHD research can be beneficial for future clinical care, enabling assessments that capture the entire spectrum of functioning, including not only specific individual disabilities, but also strengths. Taking into account strengths can balance-out deficit and resource-oriented views of ADHD in intervention and increase general societal awareness.

Personal factors

Although a diagnosis of ADHD requires the symptoms to significantly impair daily life functioning, there is a considerable knowledge gap in how diagnosed individuals experience their own involvement and engagement in everyday activities. Investigating personal factors, defined by the WHO as particular features of an individual's life that are inherent to the individual, but not part of the condition, are therefore crucial for the understanding of ADHD in daily life. Participants mentioned many personal factors to either hamper or facilitate their functioning. For example, empowerment, which involves drive functions and goal-oriented actions, was reported to aid to cope with hardships, enable academic and vocational success. Finding motivation and setting personal goals were mentioned to positively influence coping-skills and personal development, which is in line with previous qualitative research on ADHD [19]. Further, a positive attitude toward the ADHD diagnosis was experienced as a protective factor in life. Several participants acknowledged past traumatic events (i.e., getting bullied,

losing a loved one) and current life-habits (i.e., lack of physical activity, drinking alcohol) to clearly hamper individual functioning. Altogether, the results demonstrate the necessity to not only explore diagnostic status according to ICD and ICF classified functioning aspects, but also personal factors in ADHD to fully grasp individual situations, limitations and potentials.

Study limitations

The current study faced some important methodological challenges. Even though the current sample included cases from eight countries and four WHO-regions, Africa and the Americas were unfortunately not represented. Moreover, the South-East Asia region only contributed a handful of cases to the study sample, while the Western Pacific only included cases from the Far East, limiting the potential global generalization. A large proportion of the participants came from Europe, making it difficult to conduct cross-cultural comparisons within the study sample. Saturation analyses showed, however, that no candidate category would have been lost, if only data from Europe would have been analyzed. The latter indicates a good cross-cultural agreement and generalizability of the functional abilities and disabilities typical of ADHD. The primary aim of this study was not to explore cultural differences in ADHD-related functioning and environment, but to ensure cross-cultural coverage of ICF-CY candidate categories when generating evidence for the upcoming ICF core set international consensus conference. Here, experts from all WHO-regions are represented to decide on the first versions of the ICF core sets for ADHD, and additional categories might be added based on consensus, if needed. Although it is encouraged by the WHO and ICF Research Branch [29] to involve international stakeholders, analyses of cultural differences are not a mandatory part of the core set development. However, we plan for the future to explore cultural differences in ADHD functioning and environment in a separate article by pooling data from the different preparatory studies. There is a substantial value in investigating cultural influences on ADHD, as these have shown to affect diagnostic assessment and treatment options [34, 53]. Moreover, gender and age group differences were not investigated in this study, partly because of the uneven representation of females and adolescents, but also due to many confounding factors (e.g., culture, comorbidity, ADHD subtype, information sources) that might potentially lead to biased results. Compared to children and adolescents, the ICF-CY checklist for adults with ADHD in this study were mainly completed without having full access to medical records, possibly limiting the depths of clinical assessment of functioning in these cases. In future studies, it would be desirable to involve larger numbers of units specialized in adult neuropsychiatry. Interviews on children and adolescents relied for the most part on secondary informants (i.e., immediate family member), which is not unusual for child and adolescent mental health, but still might not be particularly representative of the primary perspective of young individuals diagnosed with ADHD. Even though primary informants are preferable, there are some challenges with using self-reports in younger individuals with disabilities. Young children may lack the understanding, insight or communication skills to provide valid information [13]. In addition, for children with mental health problems, disorder-specific symptoms and impairments may also affect their own assessment [59]. For example, a child with ADHD may have issues with reporting on attention problems owing to attention problems. Additionally, this study did not investigate inter-rater reliability between the investigators, mainly due to the international nature of the study and cultural and language issues associated with it. The investigators were, however, strictly instructed to seek consensus rating in their clinical teams pertaining to the cases.

Conclusions

This study examined individuals diagnosed with ADHD using the ICF-CY framework in clinical environments in eight countries and four WHO-regions. It assessed both abilities and disabilities commonly associated with ADHD across the entire lifespan, as well as environmental barriers and facilitators, and personal factors. The results from the current study complete the preparatory scientific basis for developing the first versions of ICF Core Sets for ADHD, using a formal decision-making process at a consensus conference. From these Core Sets, standardized metric tools can be developed to enhance nuanced diagnostic documentation, treatment planning, and outcome research of functioning in individuals with ADHD. The Core Sets will also guide ICF-CY assessments recommended for ADHD in ICD-11 (http://apps.who.int/classifications/icd11).

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Compliance with ethical standards

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