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Published in:
European Child & Adolescent Psychiatry

DOI (link to publication from Publisher):
[10.1007/s00787-018-1124-1](https://doi.org/10.1007/s00787-018-1124-1)

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Publication date:
2018

Document Version
Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

Citation for published version (APA):

Mahdi, S., Ronzano, N., Knüppel, A., Dias, J. C., Albdah, A., Chien-Ho, L., Almodayfer, O., Bluschke, A., Karande, S., Huang, H.-L., Christiansen, H., Granlund, M., de Vries, P. J., Coghill, D., Tannock, R., Rohde, L., & Bölte, S. (2018). An international clinical study of ability and disability in ADHD using the WHO-ICF framework. *European Child & Adolescent Psychiatry*, 27(10), 1305–1319. <https://doi.org/10.1007/s00787-018-1124-1>


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

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Received: 8 May 2017 / Accepted: 9 February 2018 / Published online: 17 February 2018
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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

Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s00787-018-1124-1>) contains supplementary material, which is available to authorized users.

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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 | <i>N</i> (%) |
|-----------------------------|-----------------------|--------------|
| 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%) | | |

^aOther marital status includes dating, long-distance relationships, live-apart, etc

^bOther educational level includes preschool and folk high school

^cOther 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/socio-cultural 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>).

Acknowledgements The development of ICF Core Sets for ADHD is a cooperative effort between the Center of Neurodevelopmental Disorders at the Karolinska Institutet (KIND) in Sweden, the ICF Research Branch, a cooperation partner within the WHO Collaboration Centre for the Family of International Classifications in Germany (at DIMDI), and the European Network of Hyperkinetic Disorders (EUNETHY-DIS). The project also received practical support by the ADHD World Organization. Guidance on this project is provided by the Steering Committee comprised of key opinion leaders in the field of ADHD from all six WHO-regions (Omar Almodayfer, Heidi Bernhardt, David Coghill, Petrus de Vries, Mats Granlund, Judith Hollenweger, Martin Holtmann, Sunil Karande, Florence Levy, Luis Rohde, Michael Rösler, Melissa Selb, Susan Shur Fen-Gau, Susan Swedo, Rosemary Tannock, Bedirhan Üstün). The development of ICF Core Sets for ADHD is supported by the Swedish Research Council in partnership with FAS (now renamed FORTE), FORMAS and VINNOVA (transdisciplinary research programs on child and youth mental health, Grant no.

259-2012-24). For this specific study, funding was also made by the National Cheng Kung University in Taiwan. This study acknowledges the support of clinical researchers, research assistants and clinicians who were involved in recruiting, rating and analyzing clinical cases. These include Sara Carucci and Roberta Romaniello (University of Cagliari), Min-Chia Weng (Department of Psychiatry, National Chen Kung University Hospital, Taiwan), Johanna Bengtsson, Christer Clas-son, John Hasslinger, Philip Ivers-Ohlsson, Micaela Meregalli, and Anna Pilfalk, (all Center of Neurodevelopmental Disorders at Karolinska Institutet (KIND), Stockholm, Sweden).

Compliance with ethical standards

Conflict of interest Soheil Mahdi declares no conflict of interest related to this work. Nadia Ronzano declares no conflict of interest related to this work. Ane Knüppel declares no conflict of interest related to this work. José Carlos Dias declares no conflict of interest related to this work. Ayman Albдах declares no conflict of interest related to this work. Lin Chien-Ho declares no conflict of interest related to this work. Omar Almodayfer declares no conflict of interest related to this work. Annet Bluschke declares no conflict of interest related to this work. Sunil Karande declares no conflict of interest related to this work. Huei-Lin Huang declares no conflict of interest related to this work. Hanna Christiansen declares no conflict of interest related to this work. Mats Granlund declares no conflict of interest related to this work. Petrus J de Vries reports no direct conflicts of interest related to this article. He has been a study steering group member of three international multi-centre trials of mTOR inhibitors in Tuberous Sclerosis Complex (TSC) sponsored by Novartis and has been co-PI of phase II clinical trials part-sponsored by Novartis. David Coghill reports grants and personal fees from Shire, personal fees from Janssen-Cilag, personal fees from Lilly, grants and personal fees from Vifor, personal fees from Novartis, personal fees from Medice, personal fees from Oxford University Press, outside the submitted work. Rosemary Tannock reports honorarium and travel costs for unrestricted talks sponsored by Shire, Lilly, Medice and Research support from Cogmed (provided software at no cost for my federally funded research studies on working memory training). Luis A. Rohde received grant or research support, and served as a consultant or in the speakers' bureau of Eli Lilly and Co., Janssen, Medice, Novartis and Shire. The ADHD and Juvenile Bipolar Disorder Outpatient Programs chaired by Dr. Rohde received unrestricted educational and research support from the following pharmaceutical companies: Janssen, Novartis, and Shire. Dr. Rohde received travel grants from Shire to take part in the 2015 WFADHD congress. He received royalties from Artmed Editora and Oxford University Press. Sven Bölte reports no direct conflict of interest related to this article. Dr. Bölte discloses that he has in the last 5 years acted as an author, consultant or lecturer for Shire, Medice, Roche, Eli Lilly, Prima Psychiatry, GLGroup, System Analytic, Kompetento, Expo Medica, and Prophase. He receives royalties for text books and diagnostic tools from Huber/Hogrefe, Kohlhammer and UTB.

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