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Original Article

Quantifying Disability in Children Challenged by Communicative and Cognitive Disorders Using the ICF-CY-Checklist: Results of a Cross-Sectional Study of a Retrospectively Assembled Cohort

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ABSTRACT

Background: The International Classification of Functioning, Disability, and Health-Children and Youth Version (ICF-CY)-check list, is a free tool, used to quantify disability. World Health Organization Disability Assessment Schedule–Children and Youth version [WHODAS 2-Children and Youth (WHO-DAS-Child)] is a less time-consuming tool, to quantify disability, based on the ICF-frame work. We aimed to quantify the disability of a group of cognitively disabled children using ICF-CY-checklist, WHODAS-Child and Vineland Social Maturity Scale (VSMS) score. We compared scores obtained using ICF-CY and WHODAS-Child, with VSMS taken as reference and also compared ICF-CY and WHODAS-Child scores. We ascertained factors associated with greater disability.
Methods: A hospital based cross-sectional study with diagnostic test evaluation.
Results: Hundred cognitively disabled children were recruited (median age 6 years, 73% male). ICF-CY median 'b,' 'd,' and total scores were 8.8 (interquartile range [IQR]: 5.95, 15.4), 23.7 (IQR: 14.9, 36.7) and 16.8 (IQR: 10.7, 27.4). On multivariable-regression-analysis, age-at-first-concern below one-year, diagnosis of autism-spectrum-disorder, family history of developmental-cognitive-disability, prematurity, low-birth-weight, motor deficits and higher-maternal-age were associated with worse cognitive ability. There was a significant negative correlation (rho = −0.50, $P < 0.001$) on comparison of ICF-CY with VSMS, and WHODAS-Child in relation to VSMS (rho = −0.42, $P < 0.001$). A positive correlation was found between ICF-CY-d-score and WHODAS-Child score (rho = 0.79, $P < 0.001$).
Conclusions: The impairment and disability of a group of children can be captured using ICF-CY-checklist. The easier to administer, WHODAS-Child, matches well with ICF-CY 'd' scores and VSMS, and can be used for quantification of disability. This quantification can help to assess burden-of-illness,

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in a geographic area or due to a particular etiology and would serve to assess the effect of an intervention on these children, uniformly across the globe.

Introduction

The United Nations Convention on the Rights of Persons with Disabilities, promotes the health, well-being, and participation of children with disabilities.[1] However, it is challenged by stigmatization, institutionalization and exclusion of these children from formal education, and economic aid. The needs of the cognitively challenged child are manifold and the caregiver stress in the family is tremendous. The quantification of the burden of the disabled child, prioritization of the need of the individual child, and estimation of the financial and medical support needed, emphasized the urgency for tools to assess the degree of disability. This was conventionally done using expensive tools such as the Weschler intelligence scale for children or the Vineland Social Maturity Scale (VSMS).[2,3] These tools are out of reach of the medical facility of developing countries due to financial reasons. Besides, they need expertise or training and supervision for their use, scoring, and analysis, and do not address all aspects of the child's disabilities. Recognizing this gap in the field, the World Health Organization (WHO) has developed the International Classification of Functioning, Children and Youth (ICF-CY) version-checklist with the questions for impairment in the child measured using 'b' scores and the disability of the child measured using 'd' scores.[4] The ICF-CY-checklist can be self-administered or reported by parent or proxy. The WHO later developed the World Health Organization Disability Assessment Schedule–Children and Youth version [WHODAS 2-Children and Youth (WHODAS-Child)] as a self-reported, more practical tool to assess the disability of children. This tool assesses the functioning of the child in the following six domains: cognition (understanding and communicating), mobility (moving and getting around), self-care (attending to one's hygiene), dressing, eating, and staying alone.[5] The ICF-CY checklist and WHODAS-Child, being universally available tools and free of cost, can be used in assessments across the globe so that there is uniformity in studies, assessments and follow-up. It would help to compare between different interventions used for rehabilitation and treatment of the neurodevelopmentally challenged child. There are very few studies that have practically utilized the ICF-CY-checklist or the WHODAS-Child to assess the disability in a child population.[6-8]

The present study aimed to quantify disability in children challenged by communicative and cognitive disorders, using ICF-CY-checklist adapted to the local language (Malayalam).[9] As secondary objectives, we aimed to translate and validate the WHODAS-Child, to assess disability in the same cohort. We aimed to compare the scores obtained using ICF-CY-checklist and WHODAS-Child, with VSMS taken as reference and also to compare the scores obtained using ICF-CY-checklist and WHODAS-Child. We also wanted to ascertain factors that are associated with greater 'disability score' obtained on applying, VSMS, ICF-CY-checklist and WHODAS-Child, in these children.

Materials and Methods

Study design and setting

We performed a hospital based cross-sectional study of a retrospectively assembled cohort with a diagnostic test evaluation component at the Institute for Communicative and Cognitive Neurosciences, Kerala, India.

Eligibility and exclusion criteria

We consecutively included, cognitively disabled children, aged 2-17 years, who sought treatment for some form of cognitive disability from the study site, from January 2023, until the sample size was met. We excluded children from whose parents we could not obtain consent and those with incomplete case sheets.

Sample size calculation

We calculated the sample size based on the number of children required to estimate the 'd' score of ICF-CY precisely. Based on a study completed in our institution, the mean 'd' ratio of ICF-CY was 39.86 with a S.D. of 19.58.[9] The sample size calculated was 92, with an accepted error in estimation of 'd' ratio of 4 (absolute precision).

Formula used: $[Z^2_{(1-\alpha/2)}]\ [SD/d]^2 = 1.96^2 \times 19.58^2/4^2 = 92$ (rounded off to 100).

$Z_{(1-\alpha/2)} = 1.96$ at 5% significance level.

Study instruments and variables

The study variables included demographics; risk factors for neonatal brain injury (prematurity, low birth weight, birth asphyxia, delivery by C-section, presence of neonatal hypoglycemia); antenatal risk factors (maternal hypothyroidism, gestational diabetes mellitus, or pregnancy induced hypertension); any abnormality on neurological examination; presence of a defined, metabolic, structural, or genetic etiology; maternal and paternal age at child birth; age at 'first concern' by the family regarding the disorder; age at presentation; relevant family history; the primary diagnosis for the cognitive disability [autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), learning disability, developmental language delay, or intellectual disability]; the second cognitive diagnosis, if any; and regression at any point in life. The major affection in the child was termed as the primary diagnosis. When a child with ASD also has hyperactivity, by convention, his primary diagnosis was classified as ASD and that diagnosis was reinforced as ASD with ADHD and never the other way round. If a child has learning disability and ADHD, the primary diagnosis depended on the presenting symptoms and findings on assessment, which usually tell us which component is the major illness in the child. If the child's behavior was disruptive, the classification was ADHD with learning disability, and if he had minor ADHD, the classification was learning disability with ADHD. If he had definite ASD or ADHD, he was classified as ASD or ADHD, and developmental language delay would be the secondary diagnosis. If the symptoms of ASD or ADHD were minor, he was classified as 'developmental language delay.'

The diagnosis of the cognitive disability is by protocol made by the psychologist using standard tools [Indian scale for assessment of Autism/Childhood Autism rating scale for ASD and the International Clinical epidemiology network tool for ADHD.[10-12] Malin's intelligence scale for Indian children/Binet

Kamat Test/Seguin Form Board/Weschler Intelligence scale for children was used to diagnose intellectual disability and the National Institute of Mental Health and Neurosciences Index for Specific Learning Disabilities index for learning disability.[13-15] Children with a nonprogressive disorder affecting their muscle tone, posture, or movements due to an upper motor neuron pathology were classified as cerebral palsy. The cognitive disability of all recruited children was assessed using ICF-CY, WHODAS-CHILD, and VSMS. The ICF-CY has two different sets of scores; the 'b' scores quantify the impairment in the child and the 'd' scores quantify the disability that the child experiences. This study is reported in accordance with the STROBE checklist.[16]

Translated version of the ICF-CY and WHODAS-CHILD

We reported the translation of ICF-CY checklist to the local language, Malayalam and its validation, reported elsewhere.[9] We translated WHODAS-CHILD for the current study (the procedure is shown in Fig 1). The translated WHODAS-Child was given to five professionals who routinely deal with cognitively challenged children (two neurologists, two speech therapists, and a psychologist), to validate the tool qualitatively. Then the translated version was administered to 30 children with and without cognitive disability to look for confusion about any items and to seek suggestions for possible improvements of the items (cognitive interviewing). Two suggestions on question clarity were used to change the sentence construction. There was a consensus among the researchers that children who were not enrolled in school will not be asked the school-related questions at the end of the WHODAS-CHILD.

Administration of cognitive disability assessment tools

The children were called for follow-up. They were categorized into diagnostic categories based on WHO ICD-10 classification.[17] Their impairments and disabilities were quantified using the translated ICF-CY, WHODAS-Child, and VSMS. To overcome the barrier of illiteracy, all instruments were administered by trained interviewers to the parents/caregivers. Multiple family members were interviewed in each case, to circumvent information bias. While gathering the baseline information of the patient, all records with the patient were also verified so that recall bias could be minimized. The data was checked periodically for consistency and completeness by the researchers.

Steps in ICF-CY and WHODAS-Child scoring

The score obtained by a child in one domain in each questionnaire was divided by the maximum score a normal child of that age could have attained in that domain. Then the scores obtained in all domains were summed. This was then converted into a metric ranging from 0 to 100, where '0' represented no disability and '100' maximum. When there was excessive variability of scores within a domain, the child was reassessed by another researcher to confirm the score.

Statistical methods

The data was coded, entered, and analyzed using R (v4.3.1). There was no missing data. Descriptive statistics were used to quantify disability using ICF-CY, WHODAS-CHILD, and VSMS. We considered VSMS score as the reference score and assessed ICF-CY and WHODAS-Child scores using Spearman rank correlation. The primary outcomes were the quantification of the cognitive disability using ICF-CY, WHODAS-Child, and VSMS. We dichotomized the VSMS scores as 'below 70,' indicating poor cognitive ability. Those having scores above the 70th centile of ICF-CY and WHODAS-Child scores were categorized as poor cognitive ability for those indices. Odds ratios (ORs) were calculated for every potential risk factor using univariable logistic regression. Variables with a two-sided significance of 0.1 in the univariable regression analysis were evaluated using a multivariable regression model, as the multivariable analysis to determine factors that persisted to be associated with poor cognitive ability. The final model was assessed for goodness of fit using the Hosmer–Lemeshow test. Regression models were created using the package rstanarm in R. In all calculations, a *P* value of less than 0.05 indicated statistical significance.

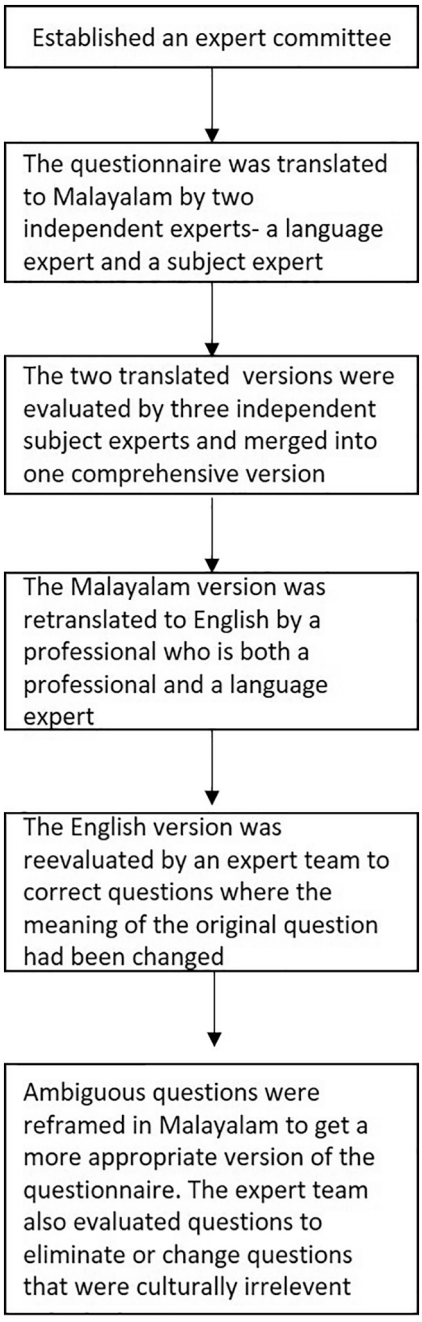

FIGURE 1. The procedure used to translate WHODAS-Child.

Ethics approval and consent for participation

The study was conducted in accordance with the Declaration of Helsinki. The institutional Ethics committee approval was obtained (IEC 008/23) from Institute for Communicative and Cognitive Neurosciences. Informed consent was obtained from all participants. Assent was taken from the children when applicable.

Observations and results

Demographic characteristics

Hundred children were recruited (median age 6 years, interquartile range [IQR]: 4.1 to 8). The process of recruitment is shown in Fig 2. The cohort consisted of 73% boys with a median age of presentation at 3 years (IQR: 2.2, 5.0) and median age at the onset of illness, 2.5 years (IQR: 1.69, 4.0). Their baseline demographic and clinical profile is given in Table 1. The median (IQR) VSMS score, ICF-CY 'b' and 'd' and WHODAS-Child were 72(63,81.25), 8.81(5.95,15.38), 23.66(14.86,36.65) and 24.79(17.50,40.36), respectively.

Correlation between the scores used

ICF-CY 'd' score (Fig 3A) and WHODAS-Child score (Fig 3B) had statistically significant negative correlation with VSMS score [(rho + -0.50, $P < 0.001$) and (rho = −0.42, $P < 0.001$)] showing that higher ICF-CY 'd' scores and WHODAS-Child scores corresponded to a moderate reduction in VSMS scores. Figure 3A, B give the visual impression of the correlation matrix, which shows that the relationships between the variables are the same across the lower and higher values of VSMS (x axis variable). However, there are only six children, who have scored less than 50 on VSMS (indicating moderate to severe disability), and therefore the numbers are inadequate to reach a firm conclusion as to whether the VSMS correlates with the ICF-CY and WHODAS-CHILD for children with moderate to severe disability scores. Further studies on moderate to severe cognitively disabled children would be needed to specifically confirm the relation of the three scales when dealing with moderate to severe cognitively impaired children.

A strong positive correlation was found between the ICF-CY 'd' Score and the WHODAS-Child score, with a Spearman's rank correlation coefficient of 0.79 ($P < 0.001$) (Fig 3C). This indicates that as the ICF-CY 'd' Score increases, the WHODAS-Child score tends to increase as well.

Predictors associated with bad cognitive ability on univariable regression analysis

Family history of developmental cognitive disability was associated with a lower VSMS score (worse cognitive ability) [OR; 0.27 (95% confidence interval [CI]: 0.11, 0.63; $P = 0.003$)]. The presence of ASD was also significantly linked to a lower VSMS score, [OR; 0.35 (95% CI: 0.15, 0.80; $P = 0.013$)]. Age at first 'parental concern', below 1 year was significantly associated with a lower VSMS score, [OR; 0.26 (95% CI: 0.07, 0.86; $P = 0.035$)].

A significantly higher ICF-CY 'd' score (worse cognitive ability) was seen in children whose illness was first recognized below

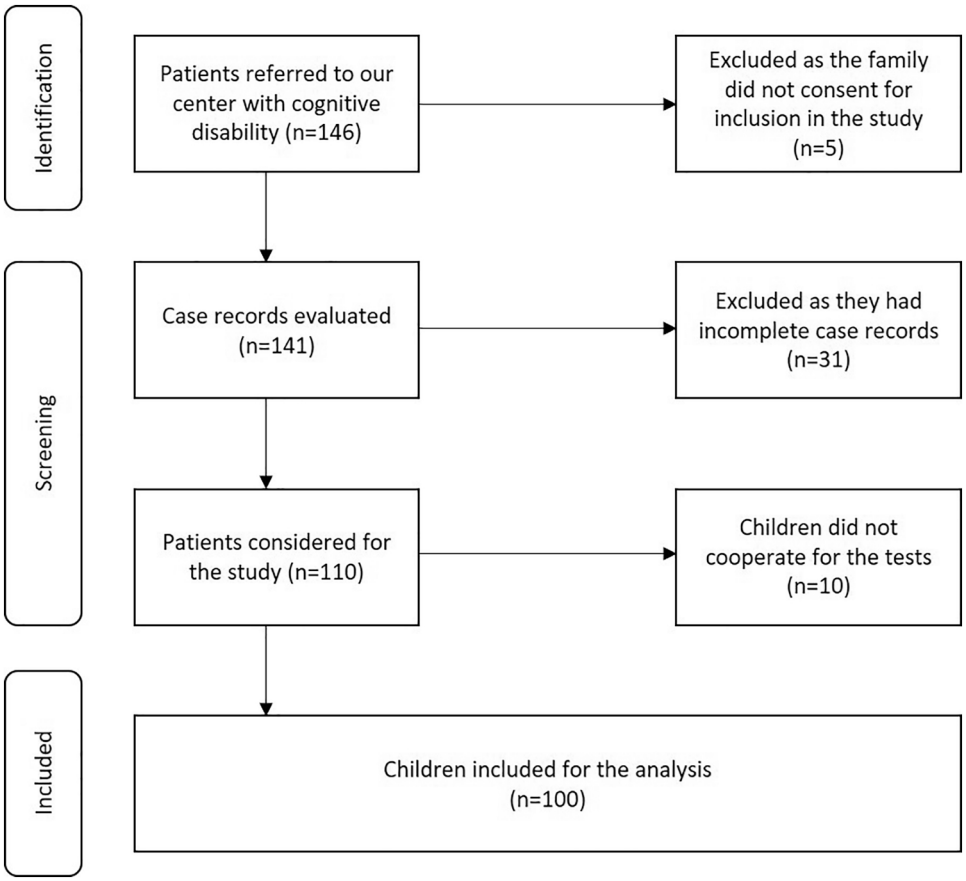

FIGURE 2. The process of recruitment in this study.

TABLE 1.
Baseline Demographic and Clinical Profile of the Cohort

Variable	n = 100*
Age (years); median(IQR)	6.0 (4.1, 8.0)
Gender (male)	73 (73%)
Age at presentation (years); median (IQR)	3.00 (2.20, 5.00)
Age at onset of illness (years); median (IQR)	2.50 (1.69, 4.00)
Latent period for presentation (years); median (IQR)	0.50 (0.00, 1.03)
Maternal age at child birth (years); median (IQR)	28.0 (25.0, 30.3)
Paternal age at child birth (years); median (IQR)	32.0 (30.0, 35.0)
Family history of developmental cognitive disability	34 (34%)
Pregnancy induced hypertension	15 (15%)
Gestational diabetes mellitus	19 (19%)
Hypothyroidism in mother during pregnancy	13 (13%)
Prematurity	14 (14%)
Birth asphyxia	10 (10%)
Low birth weight	9 (9.0%)
Mode of delivery (LSCS)	60 (60%)
Hypoglycemia in the neonatal period	8 (8.0%)
Regression at any point of life	29 (29%)
Presence of motor deficits in the child	5 (5.0%)
Diagnosis	
Attention deficit hyperactivity disorder	16 (16%)
Autism spectrum disorder	39 (39%)
Cerebral palsy	2 (2.0%)
Developmental language disorder	13 (13%)
Global developmental delay	3 (3.0%)
Intellectual disability	11 (11%)
Learning disability	16 (16%)
Associated diagnosis†	
Attention deficit hyperactivity disorder	49 (49%)
Autism spectrum disorder	4 (4.0%)
Cerebral palsy	1 (1.0%)
Developmental language disorder	15 (15%)
Intellectual disability	6 (6.0%)
Learning disability	8 (8.0%)
No associated diagnosis detected	12 (12%)
Seizure	5 (5.0%)

* n (%).
† Second cognitive disability noted in the same child.

1 year (OR: 3.45, 95% CI: 1.04, 11.8, $P = 0.042$). Children diagnosed with ASD were significantly more likely to have higher ICF-CY 'd' scores compared to those without this diagnosis (OR: 3.16, 95% CI: 1.30, 7.88, $P = 0.012$).

A higher ICF-CY b score, indicating poor cognitive ability, was seen in children with a family history of developmental cognitive disability (OR: 2.68, 95% CI: 1.11, 6.61, $P = 0.029$). The presence of motor deficits in the child was strongly associated with higher ICF-CY 'b' scores (OR: 10.6, 95% CI: 1.49, 213, $P = 0.038$). Children with an age at first recognition of the illness below one year (OR: 7.07, 95% CI: 2.08, 28.3, $P = 0.003$) was strongly associated with higher ICF-CY 'b' scores.

Higher WHODAS-Child scores (poor cognitive ability) were significantly associated with the presence of motor deficits (OR: 11.2, 95% CI: 1.57, 225, $P = 0.034$). Additionally, 'age at first concern' below one year was associated with a significantly higher WHO-DAS score (OR: 5.03, 95% CI: 1.52, 18.3, $P = 0.009$). A diagnosis of ASD was also strongly associated with higher WHODAS scores, with children diagnosed with ASD having nearly four times the odds of being in the higher score group (OR: 3.90, 95% CI: 1.60, 9.91, $P = 0.003$).

Multivariable logistic regression

Children with an age at 'first concern', below one year had significantly lower odds of scoring higher (higher score indicating better cognitive ability), on the VSMS (OR: 0.17, 95% CI: 0.04, 0.65, $P = 0.013$) (Table 2). Similarly, a diagnosis of ASD was associated with significantly reduced odds of higher VSMS scores (OR: 0.25, 95% CI: 0.09, 0.63, $P = 0.005$). Furthermore, a family history of developmental cognitive disability also significantly lowered the odds of higher VSMS scores (OR: 0.24, 95% CI: 0.09, 0.60, $P = 0.003$).

Children with an age of 'first concern', below one year (OR: 6.00, 95% CI: 1.53, 25.6, $P = 0.011$), diagnosis of ASD, (OR: 5.44, 95% CI: 1.96, 16.9, $P = 0.002$) and prematurity were significant predictors of high ICF-CY 'd' scores (OR: 3.80, 95% CI: 1.01, 15.0, $P = 0.048$). Family history of developmental cognitive disability, lost its significance.

Children with initial 'parental concern', below one year, (OR: 9.21, 95% CI: 2.31, 43.5, $P = 0.003$), maternal age at childbirth >32 years (OR: 4, 95% CI: 1.29, 12.5, $P = 0.017$) and family history of developmental cognitive disability (OR: 3.29, 95% CI: 1.16, 9.96, $P = 0.028$) had substantially higher odds of higher ICF-CY 'b' scores. Presence of motor deficits in the child lost its significance.

Low-birth-weight was associated with a significantly higher WHODAS-Child score (OR: 7.45, 95% CI: 1.03, 60.7, $P = 0.049$). The presence of motor deficits in the child dramatically elevated the odds of higher WHODAS-Child scores (OR: 20.9, 95% CI: 2.05, 528, $P = 0.021$). An age at first 'parental concern' below one year was a strong predictor of increased disability, as reflected by higher WHODAS-Child scores (OR: 13.0, 95% CI: 2.64, 82.9, $P = 0.003$). Diagnosis of ASD was also significantly associated with higher WHODAS-Child scores (OR: 11.6, 95% CI: 3.27, 56.2, $P < 0.001$).

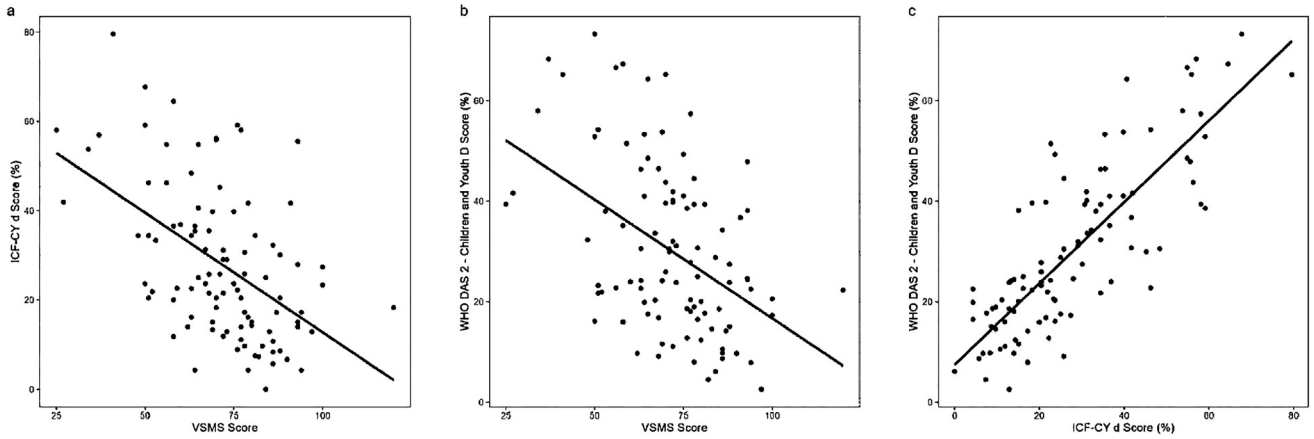

FIGURE 3. Correlation between the scores used. Foot note for figure. ICF-CY 'd' score (A) and WHODAS-Child score (B) had statistically significant negative correlation with VSMS score. A strong positive correlation was found between the ICF-CY 'd' Score and the WHODAS-Child score.

TABLE 2.
Multivariable Regression Analysis of Factors Affecting Various Scores

VSMS	OR	95% CI	*P* Value
Gestational diabetes mellitus	2.94	0.83, 12.6	0.11
Age at onset below one year	0.17	0.04, 0.65	**0.013**
Diagnosis autism spectrum disorder	0.25	0.09, 0.63	**0.005**
Family history of developmental cognitive disability	0.24	0.09, 0.60	**0.003**
ICF-CY 'd' score			
Age at onset below one year	6.00	1.53, 25.6	**0.011**
Diagnosis autism spectrum disorder	5.44	1.96, 16.9	**0.002**
Family history of developmental cognitive disability	2.55	0.95, 7.03	0.064
Prematurity	3.80	1.01, 15.0	**0.048**
ICF-CY 'b' score			
Age at onset below one year	9.21	2.31, 43.5	**0.003**
Maternal age at child birth more than 32 years	4	1.29, 12.5	**0.017**
Family history of developmental cognitive disability	3.29	1.16, 9.96	**0.028**
Presence of motor deficits in the child	5.27	0.59, 114	0.2
WHODAS-Child			
Prematurity	2.18	0.42, 11.3	0.3
Low birth weight	7.45	1.03, 60.7	**0.049**
Age below 5 years	1.94	0.65, 5.93	0.2
Presence of motor deficits in child	20.9	2.05, 528	**0.021**
Age at onset below one year	13.0	2.64, 82.9	**0.003**
Diagnosis autism spectrum disorder	11.6	3.27, 56.2	**<0.001**

Bolded values indicate statistical significance.
Abbreviations:
CI = Confidence interval
OR = Odds ratio
VSMS = Vineland social maturity scale

Discussion

We have quantified the disability in a group of children with cognitive disability using ICF-CY check list and the WHODAS-Child. As the cohort was heterogenous and included children with any cognitive disability, including learning disability, language delay, ADHD, ASD, and intellectual disability, the median VSMS was 72 (borderline disability). This corresponds to the quantification of disability using ICF-CY checklist where this cohort has a median 'd' score of 23.66, a median 'b' score of 8.81, and a score of 24.8 on the WHODAS-Child (all corresponding to less cognitive disability, as these tools give higher scores as the cognitive disability increases). Ours is the first attempt in India to apply these WHO tools in a clinical setting to quantify the disability among children with cognitive impairment. We have illustrated that the two tools are comparable to the time tested VSMS (expensive and needing expertise). The strong correlation between the three scales could be due to the presence of the same 'disability latent variable' in them. We have also demonstrated that the WHODAS-Child, a more user-friendly tool compared to the elaborate ICF-CY, yields results that match each other. All the three tools are similar in that they are etiologically neutral. The WHO-devised, universally available tools can be used to assess rehabilitative programs for children with cognitive disability and to answer real-world questions regarding these children. The administration of these tools (WHODAS-Child and ICF-CY) is relatively easy, less time consuming, and could be taught in a span of a few days to the research assistant. Being a self-report questionnaire makes it friendlier to use. The fact that it has been translated to 47 different languages makes it easy to compare research in different parts of the world.[18] Besides, the ICF-CY and WHODAS-Child assess not only the individual (his body and person) but also his interaction with the society.

We had more boys in our cohort which matches most studies on cognitive disability in children.[19-21] The demographic profile of the cohort is remarkable as the median age of presentation is 3 years, which is rather early for a tertiary referral center and may be reflective of the better educational status in the state of Kerala in India. The latent period for the family to present to the facility was also short, possibly due to the high rate of literacy in the state.

The factors that we garnered from literature and what we thought could be major factors for the cognitive disability (maternal and paternal age at child birth; antenatal factors like gestational diabetes mellitus, pregnancy-induced hypertension, hypothyroidism in the mother; the natal factors like prematurity, C-section delivery, low birth weight, birth asphyxia; and neonatal hypoglycaemia) were seen in small numbers only. More remarkable, was a family history of developmental cognitive disability (34%) and regression of already acquired milestones (seen in 29%). This points to the possibility of a genetic basis for the cognitive disability and could be representative of the nature of referral to our center. ASD was the commonest disorder captured and could be attributed to referral bias as other cognitive disabilities that cause less disability, fail to get referred in large numbers to our center (mistakenly labeled as an 'Autism center' by the community). Only 5% of the cohort had seizures as comorbidity, as the institution has limitations to cater to emergency footfall and children with seizures are referred to other institutions with emergency services.

There are scarce studies that assess the factors that we have used, to predict a worse cognition in cognitively disabled children while using the three different scales (ICF-CY, WHODAS-Child, and VSMS). A family history of cognitive dysfunction, a diagnosis of ASD and a younger age at initial 'parental concern' about cognitive dysfunction was associated with worse cognition when VSMS was the tool for quantification of cognitive disability and the latter two and prematurity, when ICF-CY 'd' scores were applied. Since we have included children with learning disability and ADHD, it is logic to expect that children with autism would have greater cognitive disability. However, such a comparison is not available in the existing literature. No study has so far addressed the effect of family history on severity of the cognitive dysfunction. The association of positive family history to poor scores possibly points to an underlying inborn error of metabolism or a monogenic disorder causing more severe disability than the disability associated with a perinatal risk factor. A younger age at onset, which is concordant with our observation, has been associated with a worse cognition in children with epilepsy using the digit forward test in a recent study from the United States.[22] Worse language development has been recorded in children with ASD, in a series from China, when there was an earlier age of 'first concern'.[23] Prematurity has been consistently associated with bad motor and cognitive outcome among disabled children, but no manuscript in the available literature has explored the effect of prematurity on the severity of cognitive disability. The late days of gestation are critical in the development of the brain, witness axonal growth, oligodendrocyte differentiation, and migration of neurones. Premature delivery of a baby disrupts these processes and result in long lasting deleterious effects. When using the impairment score 'b' of the ICF-CY; maternal age >32 years, in addition to family history of cognitive impairment and age of 'first concern' predicted, worse cognitive ability. Very young and advanced maternal age has been associated with risk of ADHD and learning disability.[24] Advanced paternal age has been linked to greater disability in children with cognitive dysfunction.[25] However, we could not find association

with advanced maternal age, when the VSMS score, WHODAS-Child, and the ICF-CY 'd' scores were applied on this cohort. Motor deficit in the child was associated with worse cognitive ability when using the ICF-CY 'b' scores. Though this lost significance on multivariate analysis, this association was concordant with other series that had addressed the same point.[26-29] The WHODAS-Child scores showed association of worse cognitive ability with early 'age of first concern,' low birth weight, motor deficits in the child, and a diagnosis of ASD. Extreme low birth weight has been well recognized as a risk factor for severe cognitive dysfunction.[30-32] Among the risk factors identified, age at 'first parental concern' retained significance on multivariate regression using all the assessment tools, emphasizing that earlier manifestation of symptoms possibly also signifying more profound impairment, points to a bad prognosis.

A standard scoring method for WHODAS-Child and ICF-CY has not been stated by the WHO. To score the WHODAS-Child and ICF-CY, we used the scoring suggested by other authors.[5] The score obtained by the child was divided by the possible score for a child of that age for that item and converted into a percentage. This is indeed, a good method to score the WHODAS-Child and ICF-CY, in children, as we are dealing with a wide age range, and the capability of the child will vary based on the child's age. In fact, school-related questions, as well pointed out by Scorza et al.,[5] cannot apply to a child who is not attending school due to motor or cognitive hurdles.

There was a significant negative correlation between the ICF-CY 'd' score and VSMS score (rho $= -0.50$, $P < 0.001$), the WHODAS-Child score and VSMS score (rho $= -0.42$, $P < 0.001$) and a positive correlation between ICF-CY 'd' score and WHODAS-Child score (Spearman's rank correlation coefficient of 0.79 ($P < 0.001$). This research shows that the easy to administer WHODAS-Child and ICF-CY are reliable tools to measure functional disability in children with developmental disorders in low-resource settings. It has the potential to be integrated into global child health programmes. In addition, the two scales assess the functional ability of the child in addition to the cognitive disability. More studies are necessary to assess other properties of the tool especially in different age groups and contexts. Both the ICF-CY and the WHODAS-Child are functional outcome assessments that can be used for all disease conditions and across all cultural groups.

Limitations

The current study has been done in a specialized neurology tertiary care center for children with neurological disorders. So, the results may not be generalizable to a general hospital setting and community settings. Children with perinatal insults are not included in this cohort due to referral bias. Our results may be limited to a cognitively disabled cohort because children with motor problems and seizures do not frequent this institute. Families who refused to participate or did not return a signed consent form were not included, producing a selection bias. Recall bias, which is inherent in all retrospective studies, must be a limitation in this study, though we tried to corroborate every statement by verifying documents available with the family. There was an uneven representation of females which could have added to bias. The under-representation of children with moderate to severe disability in the cohort studied was indeed a drawback which has to be addressed in future studies. However, because of the large number and the wide spectrum of disease categories, identified in this study, we presume that the results are indeed representative of the cognitively challenged children community at large.

We used the same sample for the validation of multiple tools, and we did not perform a sample size calculation for the analytical part of the study (the comparison of different tools). However, these analyses were our secondary objectives.

Conclusions

The impairment of a group of cognitively challenged children can be captured using the ICF-CY-checklist using the 'b' scores, their disability can be captured using the 'd' scores and the total scores can also be used to quantify disability and impairment. The WHODAS-Child scores match very well with the ICF-CY scores, and can also be used for quantification of the disability of these children. This quantification can help to assess burden of illness in a geographic area, the burden due to a particular etiology or due to a particular type of cognitive disability. This would serve as a framework for fund and resource allocation to different areas and different patient populations. It would also serve to assess the effect of an intervention on these children. This universal and freely available instrument can also serve as a common tool to assess these children uniformly across the globe.

Our data enhance previous findings of predictors for bad cognitive function in the cognitively disabled child. In summary, disabled children and their needs are in the limelight today with huge strides in research to which our findings are very likely to contribute. WHODAS-Child and the ICF-CY-checklist seem to be reliable self-report instruments for the assessment of disability. The need of the hour is to find out what would be a meaningful clinically important minimum change in the WHODAS-Child score or the ICF-CY-score to state that an intervention used, is indeed making a change in the child. If this "minimal clinically important difference" score for the two scales is established, the place of these 'free' tools in future would be unmatched. Besides, the psychometric properties of these tools should be studied in different age groups and in disease specific groups.

CRediT authorship contribution statement

Mary Iype: Writing – review & editing, Writing – original draft, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **T.S. Anish:** Writing – review & editing, Writing – original draft, Validation, Software, Methodology, Formal analysis, Conceptualization. **Sanjeev V. Thomas:** Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Hamsa Mullath:** Writing – original draft, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Murugan C. Nair:** Writing – original draft, Supervision, Resources, Project administration, Methodology, Investigation, Data curation. **Nandini Jayachandran:** Writing – original draft, Supervision, Software, Resources, Project administration, Methodology, Investigation, Data curation. **S. Sreekumar:** Writing – original draft, Supervision, Software, Resources, Project administration, Methodology, Investigation, Data curation. **Varghese Mathew:** Writing – original draft, Supervision, Software, Resources, Project administration, Methodology, Investigation, Data curation. **V.S. Santhi:** Writing – original draft, Supervision, Software, Resources, Project administration, Methodology, Investigation, Data curation. **G.S. Dhanalekshmi:** Writing – original draft, Supervision, Software, Resources, Project administration, Methodology, Investigation, Data curation. **Prasad S. Vishnu:** Writing – original draft, Supervision, Software, Resources, Project administration, Methodology, Investigation, Data curation.

Conflicts of interest

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