

Evaluation of Children with Autism Spectrum Disorder by using Common Brief Core Sets of International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY)

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ABSTRACT

Objective: To evaluate children with Autism Spectrum Disorder (ASD) by using Common Brief Core Sets of International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY)

Study Design: Cross-sectional study

Place and Duration of Study: Department of Developmental-Behavioural Paediatrics, The Children's Hospital and The Institute of Child Health, Lahore Pakistan, from Nov 2020 to Jan 2021.

Methodology: This study included 48 children with Autism Spectrum Disorder aged 3-18 years. Common Brief, a Core Set of the international classification of functioning, disability, and health in children and youth (ICF-CY), was administered to assess their functional status. Strengths and weaknesses in body structure, body function, activity and participation and environmental factors were evaluated.

Results: The functioning profile in all categories of body function, activities and participation showed severe impairment other than sleep, involuntary and voluntary functions, while complete impairment in complex interpersonal, recreational and leisure categories. Environmental factors were substantial facilitators 4(10%), moderate facilitators 6(15%), mild facilitators 3(7.5%), mild barriers 5(12.5%), moderate barriers 7(17.5%), severe barrier 1(2.5%) and complete barrier 5(12.5%) among children with Autism Spectrum Disorder (ASD).

Conclusion: Common Brief, Core Set of ICF-CY, is a comprehensive and flexible tool which provides functional information about ASD children beyond the diagnosed criteria used for ASD.

Keywords: Autism spectrum disorder (ASD), Common brief core set of the international classification of functioning, disability, and health in children and youth (ICF-CY), International classification of functioning, disability, and health in children and youth (ICF-CY).

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INTRODUCTION

Autism spectrum disorder (ASD) is a developmental disability linked with persistent impairment in reciprocal social communication, restricted interests and repetitive pattern of behaviour or activities. The symptoms of ASD begin in early childhood and limit daily functioning.^{1,2} In 2020, CDC documented an incidence of one in fifty-four children in the U.S.A.^{3,4} Pakistan Autism Society (2020) reported that 350,000 children have ASD.⁵

World Health Organization (WHO) 2001 introduced the International Classification of Function, Disability and Health (ICF). It is a tool which describes disability, disease and promotes a shared understanding of disability and disease for health professionals, researchers, and policymakers.⁶ This Classification has been available since 2007 that provides detailed information regarding the functional status of a

developing child and the impact of the environment on the child.⁷ The classification used is based upon the ICF conceptual framework for recording functional aspects and structures of the body, participation, activity limitation and relevant environmental factors.⁸

ICF-CY assesses functional status in children with developmental disorders like Cerebral Palsy, ASD, and Attention Deficit Hyperactivity Disorder (ADHD). The ICF-CY for ASD provides a means to outline the understanding of a person with ASD in a standardized way.⁹ The ICF Core Sets lead to the formation of a functional outline for each individual, emphasizing strengths and limitations, along with facilitators and barriers related to the environment.¹⁰ In Pakistan, no study has been conducted using ICF-CY in children with ASD. We use Common Brief Core Sets of ICF-CY in ASD children to capture functional abilities or disabilities and environmental influences on them. It can provide an opportunity to understand the range of support and strength these children need in a more structured way.

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METHODOLOGY

The cross-sectional study was conducted at the Department of Developmental-Behavioural Paediatrics, Children’s Hospital and The Institute of Child Health, Lahore, over three months after approval from Institutional Review Board (ERC No. 2021-222-CHICH). According to the Centers for Disease Control and Prevention (CDC, 2020), the prevalence of autism is 1 in 54.3.¹¹ Therefore, a sample size of 48 children with ASD was collected using the WHO calculator.

Inclusion Criteria: Children of either gender, aged 3-18 years with autism spectrum disorder ASD, were included in the study.

Exclusion Criteria: Children with comorbidities like cerebral palsy, Down syndrome, epilepsy, hearing impairment and visual impairment were excluded from the study.

Children were enrolled in the present study after taking written informed consent from their parents. We used Common Brief Core Sets of ICF-CY, which has 60 categories that describe the most relevant areas of functioning in ASD children with a minimal set of data. It included body functions (n=18), activities and participation (n=19) and environmental factors (n=23). Each item was rated on a scale of 0-4, where 0 depicts

barrier, +0 was no facilitator, and +4 was a complete facilitator.^{12,13} Children with ASD were assessed on Common Brief Sets ICF-CY variables, and demographic data were filled in while maintaining confidentiality. Individual administration was done. All parents were given the right to leave the study at any time or ask any question related to the research.

SPSS version 23 was used for the data analysis. Quantitative variables were expressed as Mean±SD and qualitative variables were expressed as frequency and percentages.

RESULTS

The mean age of the children was 5.00±2.5 years, and the age at the time of diagnosis was 3.00±0.56 years. Of 48 ASD children, 36(75.0%) were male, and 12(25.0%) were female. 10(20.8%) parents reported a family history of ASD, 1(2.1%) parent reported ADHD, 7(14.6%) reported speech delay, and 6(12.5%) reported behaviour problems. The mean score of CARS in ASD children was 33.38±2.05. Consanguinity was reported by 12(25%) parents of children with ASD. There were 15(31.3%) children with mild ASD, 31(64.6%) children with mild to moderate ASD, and 2(4.2%) children with moderate ASD. Table-I shows the functioning profile revealed severe disability in all body function

Table-I: Scores of Body Functioning in children with Autism Spectrum Disorder using International Classification of Functioning, Disability, and Health for Children and Youth classification (n =48)

A	Brief International Classification of Functioning Core Set	International Classification of Functioning qualifiers %age distribution among children with Autism Spectrum Disorder				
		0	1	2	3	4
1	Orientation function (b114)	0.0	0.0	37.5	56.3	6.3
2	Intellectual function (b117)	4.2	0.0	20.8	68.8	6.3
3	Global psychosocial function (b112)	0.0	2.1	16.7	66.7	14.6
4	Disposition functions (b125)	0.0	0.0	18.8	64.6	16.7
5	Temperament function (b126)	0.0	0.0	29.2	56.3	14.6
6	Energy and Drive functions (b130)	0.0	6.3	22.9	54.2	16.7
7	Sleep functions (b134)	0.0	33.3	33.3	29.2	4.2
8	Attention function (b140)	0.0	6.3	29.2	45.8	18.8
9	Memory function (b144)	0.0	12.5	39.6	41.7	6.3
10	Emotional function (b147)	0.0	2.1	33.3	47.9	16.7
11	Psychomotor functions (b152)	0.0	6.3	43.8	33.3	16.7
12	Perceptual function (b156)	0.0	8.3	41.7	43.8	6.3
13	Thought function (b160)	4.2	2.1	14.6	45.8	33.3
14	High cognitive function (b164)	0.0	0.0	8.3	64.6	27.1
15	Mental function (b167)	0.0	2.1	18.8	68.8	10.4
16	Fluency and rhythm functions (b330)	0.0	10.4	39.6	39.6	10.4
17	Voluntary function (b760)	0.0	79.2	14.6	4.2	2.1
18	Involuntary function (b765)	0.0	14.6	43.8	31.3	10.4

Note. 0 = no impairment, 1 = mild impairment, 2 = moderate impairment, 3 = severe impairment, 4 = complete impairment

no impairment and four shows complete impairment. The environmental factors (e) were rated from +0 to +4 and -0 to -4, showing the extent to which an environmental factor acts as a facilitator or barrier. In this scale, 0 represents no barrier, -4 was a complete

categories other than sleep and involuntary function category, in which children showed moderate impairment. In the voluntary function category, children showed mild impairment. The functioning profile revealed that all activities and participation

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categories showed severe impairment. However, complete impairment was shown by children with ASD in complex interpersonal, recreational and leisure categories. Table-II shows the ICF qualifier's percentage distribution for activities and participation among children with ASD. Detailed scores of

Table-II: Scores of Activities and Participation Functions in children with Autism Spectrum Disorder using International Classification of Functioning, Disability, and Health for Children and Youth classification (n =48)

B	Brief International Classification of Functioning Core Set	International Classification of Functioning qualifiers %age distribution among children with Autism Spectrum Disorder				
		0	1	2	3	4
1	Acquiring Information (d132)	0.0	10.4	12.5	60.4	16.7
2	Acquiring skills (d155)	0.0	12.5	22.9	39.6	25.0
3	Focus attention (d160)	2.1	2.1	33.3	52.1	10.4
4	Single task undertaking (d210)	0.0	6.3	47.9	37.5	8.3
5	Multiple task undertaking (d220)	0.0	0.0	20.8	37.5	41.7
6	Daily routine carrying (d230)	0.0	0.0	25.0	45.8	29.2
7	Stress handling (d240)	0.0	6.3	20.8	41.7	31.3
8	Managing own behavior (d250)	0.0	0.0	22.9	64.6	12.5
9	Receiving spoken messages (d310)	2.1	4.2	29.2	54.2	10.4
10	Receiving non-verbal messages (d315)	0.0	4.2	27.1	31.3	37.5
11	Speaking (d330)	0.0	6.3	37.5	47.9	8.3
12	Inter-personal interaction (d570)	0.0	2.1	35.4	50.0	12.5
13	Complex Inter-personal (d571)	0.0	0.0	6.3	29.2	64.6
14	Family relationship (d760)	0.0	2.1	22.9	58.3	16.7
15	School education (d820)	2.1	0.0	16.7	31.3	50.0
16	Engagement play (d880)	0.0	0.0	18.8	66.7	14.6
17	Recreation and leisure (d920)	0.0	6.3	10.4	29.2	54.2
18	Looking after ones health (d570)	0.0	4.2	22.9	56.3	16.7
19	Looking after Ones safety (d571)	0.0	2.1	18.8	45.8	33.3

Note. 0 = no impairment, 1 = mild impairment, 2 = moderate impairment, 3 = severe impairment, 4 = complete impairment

Table-III: Scores of Environmental Factors in children with Autism Spectrum Disorder using International Classification of Functioning, Disability, and Health for Children and Youth classification (n=48)

C	Brief International Classification of Functioning Core Set	International Classification of Functioning qualifiers %age distribution among children with Autism Spectrum Disorder									
		Facilitators					Barriers				
	Environmental Factors	4	3	2	1	0	0	1	2	3	4
1	Products for personal consumption (e110)	2.1	25.0	64.6	6.3	0.0	2.1	0.0	0.0	0.0	0.0
2	Products of daily life (e115)	2.1	12.5	22.9	60.4	0.0	0.0	2.1	0.0	0.0	0.0
3	Product for communication (e125)	2.1	8.3	22.9	66.7	0.0	0.0	2.1	0.0	0.0	0.0
4	Product for education (e130)	2.1	4.2	29.2	62.5	0.0	0.0	2.1	0.0	0.0	0.0
5	Immediate family (e310)	14.6	31.3	27.1	12.5	0.0	0.0	12.5	2.1	0.0	0.0
6	Extended family (e315)	4.2	14.6	41.7	16.7	2.1	0.0	12.5	4.2	4.2	0.0
7	Peers and community (e325)	0.0	12.5	45.9	14.6	6.3	0.0	18.8	2.1	0.0	0.0
8	Position authority (e330)	0.0	10.4	39.6	41.7	2.1	6.3	0.0	0.0	0.0	0.0
9	Care providers (e340)	4.2	16.7	39.6	25.0	0.0	0.0	14.6	0.0	0.0	0.0
10	Health professional (e355)	4.2	25.0	45.8	12.5	0.0	0.0	8.3	2.1	2.1	0.0
11	Other professionals (e360)	4.2	18.8	37.5	25.0	4.2	0.0	6.3	2.1	2.1	0.0
12	Individual attitude towards immediate family (e410)	10.4	37.5	20.8	14.6	0.0	0.0	14.6	2.1	0.0	0.0
13	Individual attitude towards extended family (e415)	2.1	29.2	33.3	18.8	0.0	0.0	10.4	2.1	4.2	0.0
14	Individual attitude of health professionals (e430)	0.0	10.4	64.6	18.8	2.1	0.0	0.0	4.2	0.0	0.0
15	Individual attitude of people in authority (e450)	16.7	29.2	27.1	20.8	0.0	0.0	6.3	0.0	0.0	0.0
16	Societal attitude (e460)	4.2	2.1	14.6	25.0	6.3	14.6	25.0	6.3	2.1	0.0
17	Social norms and ideologies (e465)	2.1	4.2	22.9	18.8	6.3	16.7	20.8	6.3	2.1	0.0
18	Legal services (e550)	0.0	0.0	14.6	6.3	10.4	31.3	31.3	6.3	0.0	0.0
19	Social security (e570)	0.0	0.0	16.7	35.4	8.3	8.3	27.1	4.2	0.0	0.0
20	Social support (e575)	2.1	2.1	12.5	39.6	6.3	2.1	33.3	4.2	0.0	0.0
21	Health services (e580)	6.3	14.6	35.4	25.0	0.0	0.0	10.4	8.3	0.0	0.0
22	Education (e585)	4.2	22.9	22.9	29.2	4.2	4.2	4.2	12.5	0.0	0.0
23	Labor employment services	0.0	0.0	2.1	2.1	2.1	14.6	41.7	25.0	10.4	2.1

Note. +0 = no facilitator, +1 = mild facilitator, +2 = moderate facilitator, +3 = substantial facilitator, +4 = complete facilitator, -0 = no barrier, -1 = mild barrier, -2 = moderate barrier, -3 = substantial barrier, -4 = complete barrier.

environmental factors in children with ASD using ICF-CY classification are shown in above mentioned Table-III. Among all the children with ASD, 1(2.5%) showed mild impairment, 5 (12.5%) showed moderate, 12(30%) severe, 17(42.5%) showed complete, 4(10%) non-specific and 1(2.5%) showed not applicable body functions. Among all the children with ASD, 6(15%) showed no difficulty, 4(10%) showed mild, 5(11.1%) showed moderate, 12 (30%) severe, and 11(27.5%) had complete difficulty in activity and participation. Among all the children with ASD, environmental factors were substantial facilitators in 4(10%), moderate facilitators in 6(15%), mild facilitators in 3(7.5%), mild barriers in 5(12.5%), moderate barriers in 7 (17.5%), severe barrier 1(2.5%) and complete barrier in 5(12.5%) as shown in Table-IV.

reported recurrence estimates of about 18%.¹⁶ Our study showed a family history of speech delay in 14.6%, ADHD in 2% and behaviour problems in 12.5% of children with ASD. A previous study revealed an association between a family history of mental disorders in children with ASD.¹⁷

This study found that complete impairment in the body functions domain was shown in 42.5% and severe impairment in 30% of children with ASD. The thought functions, attention, and high cognitive functioning disclosed the maximum level of impairment, followed by intellectual functioning. The slightest impairment was seen in voluntary functions. Another study reported similar impairment distribution influencing children with ASD.¹⁸

Table-IV: Frequency of Body Functions, Activities and Participation, Environmental Factors in Children with Autism Spectrum Disorder (n=48)

Body functions		Activities and participation			Environmental factors	
		Capacity		Participation		
Mild impairment	1(2.5%)	No difficulty	6(15%)	6(15%)	Substantial facilitators	4(10%)
Moderate impairment	5(12.5%)	Mild	4(10%)	4(10%)	Moderate facilitators	6(15%)
Severe Impairment	12(30%)	Moderate	5(11.1%)	5(11.1%)	Mild facilitators	3(7.5%)
Complete Impairment	17(42.5%)	Severe	12(30%)	12(30%)	No facilitator/barriers	7(17.5%)
Not specific	4(10%)	Complete	11(27.5%)	11(27.5%)	Mild barrier	5(12.5%)
Not applicable	1(2.5%)	Not specific	1(2.5%)	1(2.5%)	Moderate barrier	7(17.5%)
-	-	Not applicable	1(2.5)	1(2.5)	Severe barrier	1(2.5%)
-	-	-	-	-	Complete barrier	5(12.5%)
-	-	-	-	-	Not specific	1(2.5%)
-	-	-	-	-	Not applicable	1(2.5%)

DISCUSSION

In the present study, we describe the functional profile (body functions, activities and participation and environmental factors) of children with ASD by applying ICF-CF Common Brief Core Set to a tertiary care hospital. The functioning profile in all categories of body function, activities and participation showed severe impairment other than sleep, involuntary and voluntary functions, while complete impairment in complex interpersonal, recreational and leisure categories. Among all the children with ASD, environmental factors were substantial facilitators, moderate facilitators, mild facilitators, mild barriers, moderate barriers, severe barriers and complete barriers.

Consanguinity in parents was observed in (25%) of children with ASD in the present study. A study in India concluded that consanguineous marriages increased the risk for ASD with an odds ratio of about 3.22.¹⁴ Family history of ASD was present in 10% of children in our study. Up to 5% of children with an uncle or aunt having ASD can be anticipated to have this disorder.¹⁵ Our study showed that 4.5% of children had another affected sibling with ASD. One study

This study noted that activity and participation was the most affected area among the three functional domains. Severe impairment was seen in 30% of children with ASD. Learning, applying knowledge, and communicating skills showed the highest difficulty level. A study showed similar patterns of participation in social activities among adolescents with Autism Spectrum Disorder.¹⁹

In our study regarding the environmental domain, more than 85% of caregivers and parents stated that the products of education and play could be a facilitator to enhance their children’s aptitude. Similarly, 85% of caregivers thought that the attitudes of parents, peers and neighbours, extended family, teachers and doctors aided their child’s function, while some narrated those attitudes as a barrier. Our study finds that Common Brief ICF Core Set was an extensive and standardized framework for evaluating and treating children diagnosed with ASD in a tertiary care setting.

Individualized education plans (IEPs) for these children should be based on their functional strengths. Efforts should be made for public awareness regarding

ASD to overcome the environmental barriers so that these children get maximum support from family and society.

LIMITATIONS OF STUDY

ICF-CY Common Brief Core Sets are a comprehensive tool, but its implementation was time-consuming due to the number of details required. We conducted this study in tertiary care hospital; it should have also included community level, especially schools dealing with ASD children.

CONCLUSION

Common Brief, Core Set of ICF-CY, is a comprehensive and feasible tool, which provides functional information about children with ASD beyond the diagnosed criteria used for ASD. It also helps assess environmental facilitators and barriers for these children in the community. ICF- CY should be used by healthcare professionals dealing with children with ASD to address their needs in a more structured way.

Conflict of Interest: None.

Authors’ Contribution

Following authors have made substantial contributions to the manuscript as under:

ST & SM: Conception, study design, data analysis, drafting the manuscript, approval of the final version to be published.

AF & AA: Data acquisition, critical review, approval of the final version to be published.

EU & HA: Data acquisition, data interpretation, critical review, approval of the final version to be published.

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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