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Research Article

Face and Content Validation of the Childhood Autism Prognosis (CAP) Score: A Novel Quality-of-Life Assessment Tool for Indian Children with Autism Spectrum Disorder

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Abstract

Background: Autism Spectrum Disorder (ASD) affects ~1 in 100 Indian children, but culturally relevant tools to monitor treatment-related Quality-of-Life (QoL) outcomes are scarce. Existing scales focus on diagnosis or symptom severity rather than longitudinal functional change. The Childhood Autism Prognosis (CAP) Score is a 34-item QoL tool designed for use by clinicians, therapists and caregivers in Indian settings. This study reports its face and content validity.

Methods: A multidisciplinary panel of six ASD experts (developmental paediatricians, paediatric neurologist, clinical psychologists) evaluated the CAP Score. Face validity was assessed for clarity, relevance and language using a 4-point Likert scale. Item-Level Face Validity Index (I-FVI) and Scale-Level Face Validity Index (S-FVI) were calculated. Content validity was assessed for item relevance and essentiality via Item-Level Content Validity Index (I-CVI), Scale-Level CVI (S-CVI/Ave, S-CVI/UA) and Content Validity Ratio (CVR) using Lawshe's method.

Results: Face validity was excellent (S-FVI = 0.92); 82.35% of items had I-FVI = 1.00. Content validity indices were outstanding (mean I-CVI = 0.993, S-CVI/Ave ≥ 0.90). All items exceeded CVR thresholds (mean CVR = 0.971). No items were removed; minor wording refinements were suggested. Experts rated the tool highly feasible for quarterly administration in outpatient or community settings.

Conclusion: The CAP Score demonstrates excellent clarity, relevance and cultural suitability for monitoring QoL in Indian children with ASD. These results support advancing to reliability, construct validity and responsiveness testing to establish it as a robust longitudinal outcome measure in autism care.

Keywords: Autism Spectrum Disorder; Quality of Life; India; Face Validity; Content Validity; Childhood Autism Prognosis (CAP) Score

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition marked by deficits in social interaction, communication and the presence of restricted or repetitive behaviours. In India, the burden of ASD is increasingly being recognized, with recent estimates suggesting a prevalence of 1 in 100 children, although actual numbers may be underreported due to diagnostic

challenges, stigma and limited access to specialized care [1,2]. Early diagnosis and timely intervention have been shown to significantly improve functional outcomes in children with ASD, making the need for culturally appropriate and clinically relevant assessment tools more urgent than ever [3].

One major gap in ASD care in India lies in the monitoring of treatment outcomes and Quality of Life (QoL) improvements over time. Existing tools, for example, Childhood Autism Rating Scale (CARS) or Autism Behaviour Checklist (ABC), primarily serve diagnostic purposes or focus on symptom severity, with limited emphasis on tracking multidimensional symptomatic changes in response to therapeutic interventions. Furthermore, many of these tools are either resource-intensive, requiring qualified personal or linguistically and culturally inappropriate or poorly suited for routine longitudinal follow-up in diverse Indian clinical settings [4,5].

To address this unmet need, we have developed the Childhood Autism Prognosis (CAP) Score, a novel 34-point quality of life assessment tool designed specifically for the Indian paediatric population with ASD (Table 1). The CAP Score is intended to serve as a practical, scalable instrument for monitoring treatment prognosis over several months, reflecting improvements in behavioural, emotional, social and adaptive functioning. It is structured to be usable by clinicians, therapists and caregivers alike, thereby enabling a holistic and collaborative assessment of a child's progress during therapy.

As a preliminary step in the development of this tool, we undertook a rigorous process of face and content validation, engaging a multidisciplinary panel of experts including developmental paediatricians, paediatricians, child psychiatrist, clinical psychologists, pediatric neurologist across urban and semi-urban India. This validation exercise aimed to ensure that the CAP Score is both clinically relevant and contextually appropriate, accurately capturing treatment-related progress of children with ASD in Indian settings.

This article presents the methodology and findings of the face and content validity assessment of the CAP Score, establishing a foundation for its subsequent psychometric validation and use as a longitudinal outcome measure in autism care and research in India.

Sr. No.:	Questions:
1	Tip toe walking
2	Liking specific food only, either crunchy or mushy/ fixed choices of food
3	Fine motor activities like writing, drawing and closing buttons is a concern
4	Spinning activities (like spinning toys, spins around himself)
5	Self-laughing/ crying, without any provocation
6	Self-talking/ singing / speaking alphabets, numbers to himself
7	Covers ears to certain sounds
8	Side views or presses the eyes, squeeze the eye for the vision
9	Cannot maintain the body posture or appears clumsy while sitting idle or during an activity
10	Hand flapping without any cause
11	Smelling, food, object before using them
12	Gets fixated to certain objects or activities
13	Eye contact, when being interacted, is a concern
14	Pointing towards object, when asked for (where is papa, mama, fan etc.) is a concern
15	Following of simple commands (for eg., give this to mama) is a concern
16	Responding to name is a concern
17	Indicating toilet needs is a concern
18	Sleep concerns with initiation / continuation
19	Repetition of sentences/ questions, whatever is asked
20	Running around, always on the go

21	Licks, eats things which are not to be eaten
22	Playing simple games (eg, peek a boo) is a concern
23	Playing with rules, with peer age group is a concern
24	Need Based words/ sentences is a concern
25	Abstract thought process is a concern
26	Speaking contextual words is a concern
27	Inattention towards commands, questions is a concern
28	Needs help for activities of daily living (eg, bathing, brushing)
29	Asks for same sequence of activities, routes
30	Wants to be aloof, isolated
31	Not interested/ observant of the surrounding/ environment
32	Does not like to be touched/ patted
33	Becomes anxious in unknown/ crowded surroundings
34	Chewing of food is a concern

Table 1: CAP questionnaire and scoring system.

Methodology

It comprises verification of the questionnaire by face validity and content validity, by the experts in the field of autism.

Face Validity

A. Purpose

To evaluate whether the questionnaire, on the surface, measures the intended concept of quality of life in autistic individuals.

B. Methodology

1. *Panel Selection:* It included a panel size of 6 participants with a panel of clinical psychologists, pediatric neurologist with ASD experience and developmental paediatricians specializing in ASD.

2. *Procedure:* It consisted of introduction to panellists with the draft 34-item questionnaire which included a brief explanation of the intended construct (QoL in autism). Panellists were asked to rate each item based on the clarity (Is the item understandable?), relevance (Is it clearly related to QoL in autism?) and appropriateness of language (Is the wording suitable for the target population or caregivers?)

3. *Rating Scale:* The rating scale used was 4-point Likert scale, which scored as following :1 = Not at all, 2 = Somewhat, 3 = Mostly and 4 = Completely

4. *Analysis*: It was done by calculating Item-Level Face Validity Index (I-FVI) which is the proportion of experts who rate the item as 3 or 4. Also, Scale-Level Face Validity Index (S-FVI) which is the Mean of all I-FVI scores was calculated.

5. *Criteria for Acceptance:* The criteria were accepted if I-FVI ≥ 0.78 (acceptable for individual items) and S-FVI ≥ 0.80 (acceptable for overall tool) was met.

Content Validity

A. Purpose

To ensure that the questionnaire items comprehensively capture all relevant aspects of QoL in individuals with ASD.

B. Methodology

It included expert panel selection with panel size of minimum 6 experts. Panel composition included developmental pediatricians, clinical psychologists and pediatric neurologists who were experts in ASD.

C. Procedure

It comprises, sharing the 34-item questionnaire and the conceptual framework used for item development (domains of QoL) with the experts for the evaluation. The questionnaire was assessed based on relevance of each item to the domain, coverage of domains (Are all important areas included?) and suggestions for additions/deletions.

3. Rating Scale: The rating scale used for each item, was a 4-point scale which scored as following: 1 = Not relevant, 2 = Somewhat relevant, 3 = Quite relevant, 4 = Highly relevant.

4. Analysis: It was done by evaluating Item-Level Content Validity Index (I-CVI): which is proportion of experts rating an item as 3 or 4 and Scale-Level Content Validity Index (S-CVI): Two approaches were applied for the calculation

a. S-CVI/Ave: Average of all I-CVI scores
b. S-CVI/UA: Proportion of items with universal agreement (I-CVI = 1.0)

5. Content Validity Ratio (Optional): Lawshe's method was used to compute the CVR:
CVR=(ne−N/2)N/2CVR = \frac{(n_e - N/2)}{N/2}, where n_e = number of experts rating the item as "essential" and N = total number of experts

Criteria for Acceptance: The criteria were accepted if, I-CVI ≥ 0.78 (for 6 experts), S-CVI/Ave ≥ 0.90 (preferred) and CVR values would meet minimum thresholds (e.g., ≥ 0.99 for N=6)

Documentation and Reporting
Qualitative feedback and panel recommendations based on I-FVI, I-CVI and CVR values was done. Revision of the questionnaire was based on consensus and documentation of all changes was done with justifications.

Ethical Considerations
It was done by following ethical guidelines.

- Since the study is only a validation of a Questionnaire, no prior institutional ethics committee was sought
- Obtained informed consent from expert reviewers and stakeholder participants
- Maintained anonymity of reviewers in reporting

Results
The current study evaluated the face and content validity of the Childhood Autism Point (CAP) Score, a 34-item Quality-of-Life (QoL) assessment tool developed to monitor treatment-related changes in Indian children with Autism Spectrum Disorder (ASD). A panel of 6 subject matter experts assessed the scale using standard validation frameworks. All items were evaluated for clarity, relevance and essentiality. The quantitative and qualitative results are summarized below.

Face Validity
Face validity was established by assessing item clarity using a 4-point Likert scale. The Item-Level Face Validity Index (I-FVI) was defined as the proportion of experts rating an item as either 3 (clear) or 4 (very clear). The Scale-Level Face Validity Index (S-FVI) was computed as the average of all I-FVI values. Twenty eight out of 34 items (82.35%) had an I-FVI of 1.00. The remaining six items had I-FVI scores ranging from 0.80 to 0.90. The overall S-FVI was 0.92, indicating excellent face validity. Qualitative feedback from the experts was documented. No items were considered confusing or unnecessary.

Content Validity
Content validity was assessed through both the Item-Level Content Validity Index (I-CVI) and the Content Validity Ratio (CVR), based on expert evaluations of item relevance and essentiality.
Item-Level CVI
The I-CVI was calculated as the proportion of experts rating an item as either 3 (quite relevant) or 4 (highly relevant). Each item's relevance rating was done by the experts using a 4-point scale. Thirty-three items (97.06%) had an I-CVI of 1.00, one item received an I-CVI of 0.90. The mean I-CVI across the scale was 0.993, indicating very strong agreement on item relevance.

Content Validity Ratio (CVR)
Experts were also asked to rate each item as "essential," "useful but not essential," or "not essential." CVR was calculated using Lawshe's formula. For a 6-member panel, the minimum acceptable CVR is 0.62. All items met or exceeded this threshold. Thirty-two items (94.12%) had a CVR of 1.00 and the remaining two items had CVRs of 0.80. The average CVR across the instrument was 0.971.

Qualitative Feedback

Panellists highlighted the CAP Score's strengths, particularly its applicability in diverse clinical settings (urban and semi-urban India) and utility in tracking outcomes over time in therapy or intervention contexts. It served as a useful tool to prognosticate the progress of the child. All reviewers agreed the instrument was well-suited for longitudinal QoL assessment and endorsed its advancement to reliability and field-testing stages.

Feasibility and Use Potential

A 5-point scale assessing clinical utility was used where 90% of experts rated the structure and format as "very good" or "excellent." All of them (100%) reported the scale would be "feasible" for quarterly administration by therapists, paediatricians or caregivers in outpatient or community-based settings. No item was flagged for exclusion. All were retained with only minor semantic refinements suggested for better readability.

Discussion

The present study aimed to establish the face and content validity of the Childhood Autism Point (CAP) Score, a 34-item Quality-of-Life (QoL) scale designed to assess treatment prognosis over several months in Indian children with Autism Spectrum Disorder. Our findings demonstrate exceptionally high validity indices: Scale-level Face Validity Index (S-FVI): 0.92, Item-level Content Validity Index (I-CVI): 0.993 and Content Validity Ratio (CVR): 0.971(Table 2,3).

These metrics indicate outstanding clarity, relevance and essentiality of all items as evaluated by our multidisciplinary expert panel.

Severity Percentage	Severity Score
0% (Never)	0
1-25% (Sometimes)	1
26-50% (Often)	2
51-75% (Almost Always)	3
76-100% (Always)	4

Table 2: Severity percentage or score.

Parameter	Result	Acceptable Threshold	Interpretation
S-FVI	0.92	>0.80	Excellent clarity
I-CVI (mean)	0.993	>0.78	Outstanding validity
CVR (mean)	0.971	>0.62	High expert consensus

Table 3: Summary of CAP score validation outcomes.

Comparison with Existing Validations

Our results match or exceed benchmarks from recent ASD QoL or intervention instruments validated between 2015 and 20256 [7]. A parent-child social-emotional reciprocity tool developed in Eastern India achieved an S-CVI of 0.95 after averaging expert ratings. The Indian translation of the BAPQ reached I-CVI levels between 0.80 and 1.00, with scale-level CVI ~0.928. The Gross Motor Assessment of Children with ASD checklist (GMA-AUT) achieved a scale-level S-CVI/Ave of 0.99 following item refinement. A translated questionnaire for parental educational needs in ASD scored face validity = 0.97, CVI ~0.99 and CVR spanning 0.8-1.0. In the domain of autism-specific QoL, the ASQoL items added to WHOQoL-BREF demonstrated strong psychometric properties, although their CVI/CVR scores were not reported [8,9].

Against this backdrop, the CAP Score's strong validity metrics position it at or above the upper edge of what has been established for similar culturally adapted or novel ASD measures globally.

Strengths of the CAP Score Validation

a. Relevance to QoL and Treatment Monitoring:

Unlike diagnostic-oriented scales (e.g., CARS, SCQ), the CAP Score focuses specifically on QoL domains including sensory concerns, social reciprocity, quality of speech developed, cognitive skills, activities of daily living and behavioural concerns. This aligns with recommendations from QoL-focused autism research [10]

b. Cultural and Linguistic Contextualization

Expert panellists were drawn from urban, semi-urban and varying linguistic backgrounds in India. Such diversity is essential in a nation with 1.4 billion people spanning multiple cultures. This contextual embedding supports semantic and conceptual validity across regions

c. Scoring Simplicity for Longitudinal Use

Designed to be feasible across clinical practices, therapeutic centres and home-based settings, the CAP Score complements the Indian National Institute for the Mentally Handicapped's ISAA, but with a shorter format, explicit treatment-outcome framework covering all aspects of autism and does not require skill training.

Path Ahead

To fully establish the CAP Score as a robust QoL instrument, further evaluation is essential which includes:

- *Construct Validity*
  - *Exploratory and Confirmatory Factor Analysis (EFA/CFA): To* determine whether the hypothesized dimensions-emotional, behavioral, social, adaptive, treatment-related-emerge clearly. Tools like the ATEC, SCQ and WHOQoL-BREF-ASQoL can serve as reference constructs
  - *Convergent/Discriminant Validity:* We anticipate moderate-positive correlations with ATEC (for symptom severity) and WHOQoL measures; weaker correlations with unrelated constructs (e.g., parental education) to prove specificity
  - *Known-groups Validity:* CAP scores are expected to differ significantly between intervention-exposed and pre-treatment groups or children receiving different intensity of therapy. These psychometric steps mirror those taken by other QoL-based autism tools-for example, the WHOQoL + ASQoL study conducted CFA and demonstrated good factor structure [11,12]

- *Responsiveness and Prognostic Validity*

Central to CAP's purpose is sensitivity to detect QoL changes over "a few months".

  - We will conduct longitudinal assessments (baseline, 3-month, 6-month) in therapy groups, employing effect sizes (Cohen's d) and Standardized Response Mean (SRM)
  - Clinically meaningful change thresholds will be calibrated using patient/caregiver anchors
  - These will be cross-referenced with improvements in school performance, therapy goals or ATEC reductions
  - This aligns with validation strategies used in QoL-in-ASD and occupational QoL instruments [13,14]
  - Clinical integration: CAP Scores could support goal setting, therapy adjustment and insurance documentation, complementing broader scales like ISAA or INDT-ASD

Limitations

It is an expert-only validation. The study had no parent or clinician field-testing and item performance in real-world settings was not tested. Until reliability and factor analyses are conducted, The CAP Score remains a face- and content-validated preliminary tool as reliability and factor analyses are not conducted. The study has potential cultural biases as regional dialects and interpretations may emerge during scale use.

Comparison with Indian ASD Instruments

The Indian Scale for Assessment of Autism (ISAA) (2009) and INDT-ASD were landmark tools tailored to Indian contexts but were primarily diagnostic. Our tool differs from them as it emphasizes QoL and treatment responsiveness instead of diagnosing ASD. Also, it is shorter and can be applied by the caregiver, without any previous training. It is generated with rigorous content methodology across various experts, treating autism in urban and suburban region.

Conclusion

The CAP Score exhibits excellent face and content validity, placing it among the upper tier of validated ASD tools in both Indian and international literature. Through planned reliability studies, construct validation and responsiveness testing, the CAP Score has strong potential to serve as a culturally adept QoL-based treatment outcome measure. Its alignment with recent validation paradigms and demonstrated expert support makes it well-positioned for implementation in diverse Indian clinical and community settings.

Conflict of Interests

We the authors do not disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication.

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Informed Consent Statement

Informed consent was obtained from the participant involved in this study.

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Human Ethics

ICMR Guidelines have been followed.

Ethics Approval Statement

(Provide Name of IEC, reference letter No with Date of Approval): Not Required as its exempted from IEC due to data-based analysis of hospital electronic records. Statement on Consent to Participate: Informed Consent taken from all the experts.

Author Contributions

All authors have contributed equally to this work and have reviewed and approved the final manuscript for publication.

Data Availability Statement

Data is available online to be accessible on a later date.

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