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Original Article

Development and Validation of Psychological Adaptation Tool (PAT) for Children with Chronic Illness

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Abstract

Introduction: Children with chronic illnesses experience many difficulties in adapting to their conditions. A review of the literature indicates a lack of instruments to measure this concept. Therefore, the aim of this study was development and validation of psychological adaptation tool (PAT) for children with chronic illness.

Methods: An exploratory mixed method design was used to develop and validate the PAT for children with chronic illness. The study was conducted in the paediatric OPD (outpatient department) and IPD (in patient department) at All India Institute of Medical Sciences, Jodhpur, and Rajasthan. It took place in three phases (phase one: item development, phase two: tool development, phase three: tool evaluation) and a final tool of 16 items, classified into four domains was made. The method of convenient sampling was used to select 160 study participants. The reliability was tested using Cronbach's alpha. The construct validity of the tool was checked with exploratory factor analysis.

Results: The results of study suggest that PAT is a valid and highly reliable tool. The content validity index was 0.96. The Cronbach's alpha value for the entire 16 items of PAT was 0.850 which was found to be good. The principal component analysis yielded 4 factors (Cognitive, conative, self-efficacy and coping strategies) with an eigenvalue of more than 1.00.

Conclusion: The result of this study has shown that PAT is a feasible highly reliable and valid tool.

Introduction

The concept of adaptation is omnipresent in psychology.[1] Adaptation is described as the ability to accept and respond to changes in the internal and external environment with the right attitude and behaviour.[2]

Piaget defined adaptation as a process through which children modify their actions, ideas, or plans in response to environmental changes in order to reach a condition of cognitive equilibrium.[3] A chronic illness or medical condition is a health issue that impacts a child's daily activities, lasts three months or more, and necessitates repeated hospitalisations, home health care, and/or intensive medical attention.[4] In general, chronic diseases have at least three key characteristics: They are rarely fully curable, have a long duration, and do not resolve spontaneously.[5]

Psychological adaptation is a functional change in response to environmental stimuli, in terms of sensory functioning, behavior, cognition, or emotions.[1,6-8] The theory of cognitive adaptation is based on the assumption that people possess unrealistically positive views of themselves to enhance their well-being.[9,10]

The emotional reaction to the diagnosis of a chronic illness can be a greater challenge than coping with the physical manifestations of the illness.[11-14] Children use various strategies to cope with the psychological stressors associated with chronic illness.[15]

Hospitalization is considered as most unfamiliar environment for children. Children experience psychosocial problems as a result of short and long-term impact of hospitalization.[16,17] Children undergo a variety of unpleasant situations in addition to varied physical environments, such as painful procedures and the adverse effects of chemotherapy.[18]

The need of the study is that we hope to provide academic and practical researchers with a tool that allows them to explore new aspects of children's well-being and improve their coping abilities, and, consequently, their health status. Children's psychological adaptation is an area of study that's yet to be explored. Measuring children's psychological adaptation is an important endeavour, knowing the adaptation levels of the children can guide treatment, care, education, and counselling planning for optimum growth and development during their chronic illness period.[19,20] On other hand, parents were chosen as the instrument completers due to the uncooperativeness of the children with the defined age group. Therefore, the aim of this study was to development and validation of psychological

adaptation tool (PAT) for children with chronic illness.

Material and Methods

An exploratory mixed method design was used to conduct the study. The PAT was developed in three phases. Figure 1 shows the schematic representation of the research.

Phase 1: Item Development Phase

This phase has two steps

1. Identification of Domain

Extensive Review of Literature

For the identification of domains, an extensive review of literature was carried out in order to explore the psychological adaptation of children with chronic illness. The review had been conducted from various journals, articles and other previous studies using the electronic databases PubMed, MEDLINE, CINHAL, Cochrane Library and Google Scholar. The areas focused in this review were related to the psychological adaptation children undergo who is suffering from chronic illness. The BOOLEAN operators, AND/OR was used for review, using the following:

- Psychological adaptation AND Children
- Psychological adaptation AND Chronic illness
- Psychological adaptation AND Chronic illness AND children

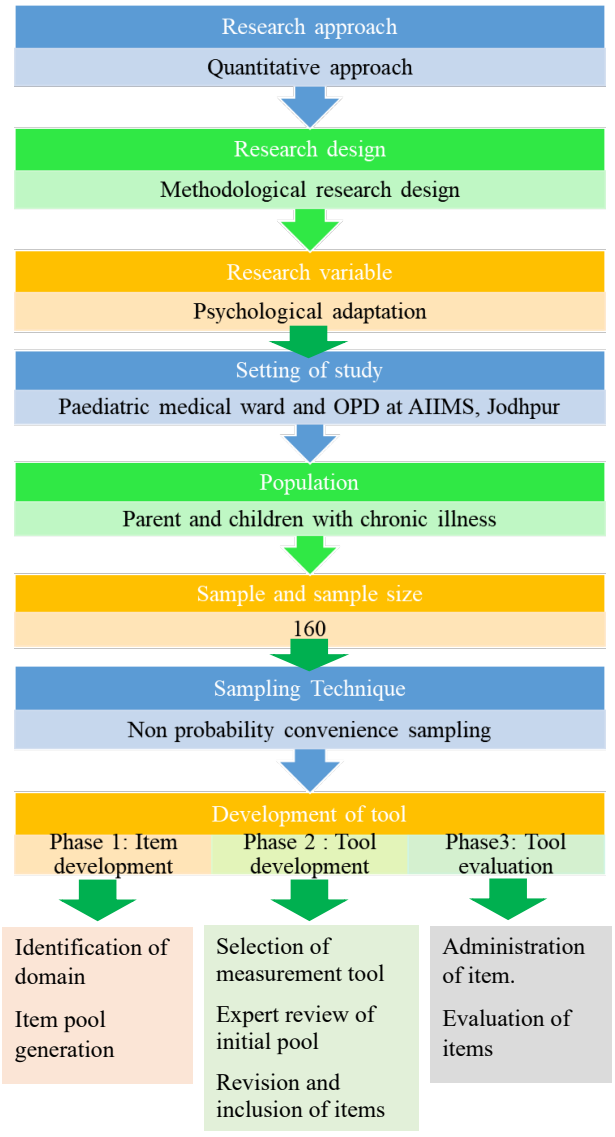

Figure 1. Systematic representation of research methodology

Focused Group Discussion (FGD)

In order to develop the items, focused group discussion (unstructured) was conducted among two groups. One group consisted of 6 Pediatric doctors and 8 pediatric nurses working in pediatric medicine unit at AIIMS (All India Institute of Medical Sciences), Jodhpur and the other consisted of 10 parents whose children were suffering from chronic illness. Both FGDs were of about 30-35 minutes duration and the responses were noted.

The components of psychological adaptation of children with chronic illness obtained from the FGDs commonly included cognitive component which included about attention, learning, memory and concentration of the child. Other components included self-efficacy which included interaction of the child or relationship with others as a component of psychological adaptation to chronic illness in children. Participants also highlighted different coping mechanism usually used by the children.

2. Item Pool Generation

An item pool was generated which consisted of 4 domains, 14 subdomain and 29 items, generated based on the content that were identified through deductive and inductive methods via literature reviews and FGDs respectively. The items generated from literature review and FGDs were summarised domain wise in following manner in Table 1.

Phase 2: Tool Development

1.Selection of measurement scale

After the generation of the item pool list of opposite adjectives pairs in accordance with the statement were selected and a 5-point semantic differential tool was prepared based on which the participants selected the response that best represent the direction and intensity of their judgement about the adaptation of their child in last 6 months.

2. Expert Review of Initial Item Pool

The review of initial pool of items was done by the expert panel through the modified Delphi process. Two rounds of modified Delphi were conducted.

Stages of Delphi

Different stages are followed in the Delphi process:

Identification and Selection of Experts

The proper accomplishment of Delphi process depends

Table 1. Summary of item pool generation

Domain/Sub-domain	Items
Cognitive domain	
Memory	Is your child less efficient at remembering things now than he/she used to be?
	Does your child misplace things more frequently now than he/she used to?
	Does your child find it difficult to remember names of friends and relative?
	Does your child remember the order of things in which any particular event occurred?
Attention	Does your child get frequently distracted by the events around?
Learning	Does your child show interest in learning new things?
Concentration	Does your child jump from topic to topic in a conversation?
	Does your child go from one assignment to another without completing them?
Conative	Does your child interact less with other people around now?
	Does your child share his/her concern about illness with you?
	Does your child make friends easily?
	Does your child have any difficulty with initiating or responding to conversation?
	Does your child behave well with his/her sibling?
	Is your child hopeful for positive outcome of treatment of his/her illness?
	Does your child believe his/her illness is a kind of punishment?
	Have you observed sudden mood change in your child because of illness?
Self-efficacy	Does your child generally maintain an adequate diet?
	Does your child take his/her prescribed medications?
	Does your child look interested in grooming him/herself?
Coping strategies	
Denial	Does your child deny to accept his disease condition?
Fantasy	Does your child say that superhero will come to save him?
	Does your child enjoy playing with his/her toys more over any other activity?
Isolation	Does your child prefer to stay alone?
Distortion	Does your child only see negative in a situation than positive?
Repression	Does your child share about the painful procedures after discharge or when at home?
Regression	Does your child begin to suck their thumb or wet the bed when they need to spend some time in the hospital?
Displacement	Does your child start hitting his toys when frustrated with the treatment procedures?
Temper tantrum	Does your child show anger when asked for hospitalization?
Avoidance	Does your child avoid talking about his disease condition?

mainly on the expert panel. Therefore, careful selection of experts should be made.

The Delphi panel for the present study consisted of 15 experts out of which 6 were from the field of paediatric nursing, 2 from the Department of Clinical and Child Psychology, and 7 from the Department of Psychiatry.

Sending Invitation to the Experts

The initial contact with the selected experts was made through mail in which a request letter was sent inviting them for the Delphi method along with the study title. Request letter was sent to 30 experts out of whom 21 had given the consent for participation. For those experts within the Institute, the correspondence was obtained through personal contact.

First Delphi Round

Once the confirmation mail was obtained, another email was sent to the experts consisting of the brief study methodology, preliminary draft of the tool and the evaluation criteria for validation of the tool, notifying them regarding the return of their suggestions to the same email id. Out of 21 experts to whom the draft was sent, 15 experts completed the first round. The first round was completed in three weeks.

Analysis of First Delphi Round Results

Once the response was obtained, the interpretation of the first round was done. The major areas of suggestion included merging of sub-domains, renaming of some domains and rephrasing of the sentences. The item related to thought (cognitive domain), global functioning (self-efficacy), repression and regression (defence mechanism) were considered irrelevant. Renaming of the domain defence mechanism as coping strategies was also suggested. Out of initial 11 items 8 items were considered as highly

relevant by all validators and 3 needed modifications. Also, out of 29 items, 7 items were considered highly significant, 5 items were rephrased, 9 were merged and 8 were considered as irrelevant by the majority of validators and therefore removed.

After interpretation of expert's suggestion from first Delphi round, first modification was made in the initial draft of tool with 29 items. Items were reviewed and revised. Further, the revised items were rearranged by assigning them to appropriate categories. The revision of initial draft was made in manner as given in Table 2.

Second Delphi Round

Invitation for the second round was sent to only those who completed the first round and feedback of first round was also sent along with the modified tool. Out of 15 experts to whom the feedback of first round was sent, 9 completed the second round. It took 2 weeks to complete the second round.

Analysis of Delphi Round Second Results

After obtaining the responses from the validators, interpretation of second round was done. There were no suggestions for section A. for section B suggestions regarding removal of items 2, 8, 15, 17, 18, 19, 21 and 26 from initial draft were accepted by validators along with merging of items. Final 16 item tool with opposite adjective pairs after Delphi modification (Table 2).

Revision and Inclusion of Items

After the expert's review of initial item pool, the tool consists of 4 domains (cognitive, conative, self-efficacy and coping strategies) with 10 subdomains (Attention, Learning, Memory, Concentration, Interaction, Denial, Isolation, Temper tantrums, Distortion, Fantasy) and 16 items. The S-CVI/ Ave and S- CVI/UA were 0.96 and 0.87 respectively. This shows good content validity.

Phase 3: Tool Evaluation

Administration of the Items to the Subjects

The final modified draft of tool consisting of 16 items that were evolved through literature review, content validation by experts, and the study was then administered to 160 parents of children with chronic illness in the study setting at AIIMS, Jodhpur, in order to test the validity and reliability. Researcher has taken the ethical approval for the current study from the institutional ethical committee. The process of data collection explained to the subjects (parents) and a written informed consent obtained from them. Confidentiality regarding the data was assured so as to get cooperation throughout the procedure of data collection. Data were collected using PAT in Hindi language and only from those who fulfil the inclusion criteria. Parents were asked to fill the 5point semantic differential tool of PAT, ranging from 1-5, with their responses between two opposite adjective pairs. The method of administration was pen and paper method. Confidentiality and anonymity of the responses maintained throughout the study.

For Reliability analysis of the PAT Cronbach alpha was calculated, to find out the internal consistency of the tool.

Exploratory factor analysis was done to find out construct validity. Principal component matrix was used to normalize the sets of data. The appropriateness of PAT was checked by Kaiser–Meyer–Olkin (KMO) test and the Bartlett test of sphericity by using Statistical Package for the Social Sciences (SPSS, version 22).

Results

Evaluation of the Items

Reliability Analysis for the PAT

The Cronbach alpha was calculated to find out the internal consistency of the tool. The Cronbach alpha value was 0.814 for the entire 16 items, which was found to be good. Since the value of Cronbach's alpha of scale increase on deletion of item 6, this item can be removed from the tool, but after discussing with the experts and considering the importance of the item it was decided to retain it.

Construct Validity Analysis for the PAT

The KMO value of the PAT was 0.886 and Bartlett's test of sphericity shows P value of < 0.001 with a χ^2 value of 586.418, which was significant. These values show the adequacy of the sample for factor analysis.

To find out the extraction communality of each item of the tool, principal component analysis method was instituted. The initial communality of each item was assured to be 1 (100%). For the PAT, extraction communality of the item was in between 0.322-0.670 (Table 3). Hence, this data was appropriate for factor analysis.

Table 4 shows total variance of the item extracted through principal component analysis. Factor extraction condenses the item into smaller number of items and is used to identify the number of underlying dimensions. Principal component analysis method was used for the extraction of factors for PAT. Principal component analysis had generated 4 factors (cognitive, conative, self-efficacy and coping strategies). The Eigen value of all the 4 factors was above 1.00. Here the principal component analysis had showed the first four factors account for 51.0% of the total variance.

Figure 2 illustrates the scree plot for the four-factor structure for the PAT. Since there is considerable discontinuity after 4th component with Eigen value of less than 1.00, four factors could be extracted.

Table 5 depicts the Rotated Component Matrix of PAT through varimax rotation. Once the factors were extracted through principal component analysis was done with Varimax with Kaiser Normalization.

The first factor had an initial acceptable loading of 7 items (Item- 1, 5, 10, 12, 13, 14, 15) (range, 0.474-0.690) accounted for 30.34% of variance with Eigenvalue of 4.85.

Table 2. Summary of the modification of the tool

Old items		Items after first modification	Items after second modification	
1.	Your child at remembering things (attentive-in attentive)	How does your child look while doing work? (Attentive-inattentive) rephrased.	1.	How does your child look while doing work? (Attentive-inattentive)
2.	Your child misplaces things (more frequently-less frequently)	Removed		
3.	How does your child remember names of friends and relatives (recall easily-face difficulty)	How does your child remember names of friends and relatives (recall easily-face difficulty)	2.	How does your child remember names of friends and relatives? (Recall easily-face difficulty)
4.	Your child at remembering things (efficient- non efficient)	How does your child remember things (efficiently-non efficiently)? rephrased	3.	How does your child remember things? (Efficiently-non efficiently)
5.	What your child does when in a conversation (concentrated-distracted)	What your child does when in a conversation? (Stick to the particular topic-jump from one topic to other) item 5 and 7 merged	4.	What your child does when in a conversation? (Stick to the particular topic-jump from one topic to other)
6.	What is your child reaction while learning new things (curious-incurious).	What is your child reaction while learning new things? (Curious-incurious).	5.	What is your child reaction while learning new things? (Curious-incurious).
7.	Your child jump from topic to topic in a conversation (Never- sometimes)	See item 5		
8.	Does your child go from one assignment to another without completing them (frequently-never)	Removed		
9.	Your child while interacting to others look (interested-indifferent)	How does your child look while interacting with others? (Interested-indifferent) rephrased	6.	How does your child look while interacting with others? (Interested-indifferent)
10.	What is your child reaction after any painful procedure? (Share his/her feelings- avoid talking much)	What is your child reaction after any panful procedure? (Share his/her feelings- avoid talking much)	7.	What is your child reaction after any painful procedure? (Share his/her feelings-avoid talking much)
11.	What is your child behaviour towards you (friendly-unfriendly)	What is your child behaviour towards other (friendly-unfriendly) item 11,12,13 merged	8.	What is your child behaviour towards other? (Friendly-unfriendly)
12.	Does your child have any difficulty with initiating or responding to conversation	See item 11		
13.	Does your child behave well with his/her sibling	See item 11		
14.	Is your child hopeful for positive outcome of treatment of his/her illness	Your child perspective towards life (positive - negative) item 14 and 24 merged	9.	Your child perspective towards life? (Positive - negative)
15.	Does your child believe his/her illness is a kind of punishment	Removed		
16.	Your child mood most of the time (steady-unstable)	Your child mood most of the time (steady-unstable)	10.	Your child mood most of the time? (Steady-unstable)
17.	Does your child generally maintain an adequate diet	Removed		
18.	Does your child take his/her prescribed medications	Removed		
19.	Does your child look interested in grooming him/herself	Removed		
20.	Your child when you ask about his/her illness (accept the illness-deny his illness)	What is your child reaction when you ask about his/her illness? (Accept his/her illness-deny his/her illness) rephrased	11.	What is your child reaction when you ask about his/her illness? (Accept his/her illness-deny his/her illness)
21.	Does your child say that superhero will come to save him	Removed		
22.	Does your child enjoy playing with his/her toys more over any other activity (never-always)	Your child spends most of the time living in (reality -fantasy) rephrased	12.	Your child spends most of the time living in? (Reality -fantasy)
23.	Most of the time your child prefers to stay (socialized-isolated)	How does your child prefer to stay? (Socialised-isolated) rephrased	13.	How does your child prefer to stay? (Socialised-isolated)
24.	Does your child only see negative in a situation than positive (always-never)	See item 14		
25.	Does your child share about the painful procedures after discharge or when at home (often-sometimes)	Your child reaction after any painful procedure (share feeling-avoid talking much) rephrased	14.	Your child reaction after any painful procedure (share feeling-avoid talking much)
26.	Does your child begin to suck their thumb or wet the bed when they need to spend some time in the hospital	Removed		
27.	Does your child start hitting his toys when frustrated with the treatment procedures	What is your child reaction when asked for hospitalization (does not react much- show anger/tantrums) item 27 and 28 merged	15.	What is your child reaction when asked for hospitalization (does not react much-show anger/tantrums)
28.	Does your child show anger when asked for hospitalization	See item 27		
29.	How does your child behave when you talk about his/her illness (courteous-rude)	How does your child behave when you talk about his/her illness (courteous-rude)	16.	How does your child behave when you talk about his/her illness (courteous-rude)

The second factor evidenced loading of 4 items out of which 3 were retained (Item- 2, 3, 4) (range, 0.419-0.806) and accounted for 7.60 % of variance with Eigenvalue of 1.21. The third factor was loaded with 3 items (Item 7, 9, 16) (range, 0.475-0.722) and accounted for 6.78% of variance and Eigenvalue of 1.086. The fourth factor evidenced acceptable loading from 3 items (Item-6, 8, 11) (range-0.533-0.631) and accounted for 6.26% of variance with an Eigenvalue of 1.00.

A factor loading of 0.4 was considered as the criteria for acceptable loading.[21] Also the items were retained within the factor in which they had higher factor loading.[22,23] The four factors were cognitive, conative, self-efficacy and coping strategies.

Table 3. Extraction communality of items through principal component analysis

	Initial	Extraction
Item 1	1.000	0.571
Item 2	1.000	0.627
Item 3	1.000	0.604
Item 4	1.000	0.670
Item 5	1.000	0.444
Item 6	1.000	0.504
Item 7	1.000	0.489
Item 8	1.000	0.494
Item 9	1.000	0.531
Item 10	1.000	0.540
Item 11	1.000	0.322
Item 12	1.000	0.374
Item 13	1.000	0.468
Item 14	1.000	0.414
Item 15	1.000	0.611
Item 16	1.000	0.495

Scoring Of Psychological Adaption Tool

The scoring of the tool was divided into five parts with score of 16 being not at all adaptable, score of > 16-32 being a little bit adaptable, > 32-48 somewhat adaptable, > 48-64 as quite a bit adaptable and > 64 as very much adaptable.

Discussion

In this study to assess the psychological adaptation of children with chronic illness a 16-item, 5-point semantic differential tool was prepared. Through literature review it was evidenced that the previously developed adaptation tool are all Likert type.[24] The reason behind selecting the

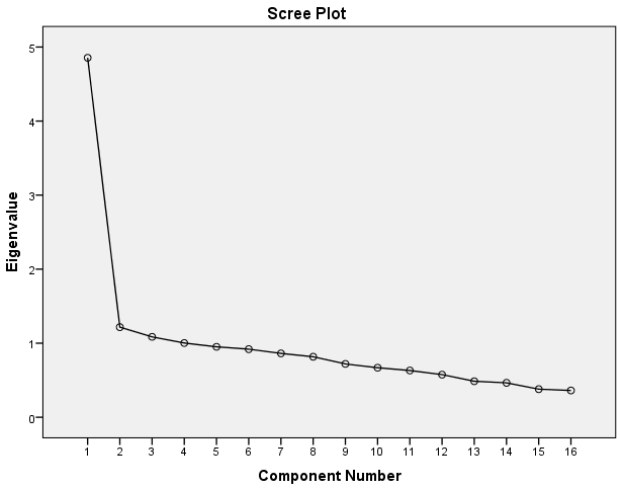

Figure 2. Scree plot for the four-factor structure for the PAT

Table 4. Total variance of the items extracted through principal component analysis

Component	Initial eigenvalues			Extraction sums of squared loadings			Rotation sums of squared loadings		
	Total	% Of variance	Cumulative %	Total	% Of variance	Cumulative %	Total	% Of variance	Cumulative %
1	4.855	30.346	30.346	4.855	30.346	30.346	2.934	18.335	18.335
2	1.217	7.607	37.953	1.217	7.607	37.953	2.006	12.538	30.874
3	1.086	6.785	44.738	1.086	6.785	44.738	1.716	10.728	41.602
4	1.002	6.264	51.002	1.002	6.264	51.002	1.504	9.400	51.002
5	0.952	5.947	56.949						
6	0.920	5.749	62.698						
7	0.862	5.390	68.088						
8	0.817	5.108	73.196						
9	0.720	4.499	77.695						
10	0.669	4.182	81.876						
11	0.632	3.947	85.824						
12	0.576	3.598	89.422						
13	0.486	3.040	92.461						
14	0.465	2.907	95.368						
15	0.379	2.371	97.740						
16	0.362	2.260	100.000						

Table 5. Rotated component matrix of the items extracted through principal component analysis

	Component			
	1	2	3	4
Item 1	0.556	0.419		
Item 2		0.526		
Item 3		0.623		
Item 4		0.806		
Item 5	0.582			
Item 6				0.631
Item 7			0.671	
Item 8				0.621
Item 9			0.722	
Item 10	0.690			
Item 11				0.533
Item 12	0.549			
Item 13	0.614			
Item 14	0.474			
Item 15	0.633			
Item 16			0.475	

semantic differential scale was that it tends to produce more accurate results than Likert scale and offer the participant a bipolar adjective pair which makes it easy to respond.[25] The PAT developed in three phases: item development, tool development and tool evaluation through seven steps. Similar methodology was used in other studies from the literature.[26,27] The final items were compiled by reviewing the literature, conducting semi-structured interviews and Delphi process.

The study unequivocally emphasizes the significance of assessing psychological adaptation in children with chronic illnesses, which is consistent with previous study finding regarding the importance of assessing psychological adaptation.[15,24] Additionally, the study discusses the need of taking into account the psychological component, which is more frequently disregarded, in children who are living with chronic disease and also the lack of tools for assessing psychological adaptation in paediatric population.

Four domains were identified to measure the psychological adaptation with PAT those were cognitive, conative, self-efficacy and coping strategies. Studies looking at illness-related coping methods also showed that children with chronic illnesses used cognitive adaption techniques more frequently.[28]

Although the PAT represents an important methodological advance in the area of children's psychological adaptation, its limitations must be recognized. First, research findings cannot be generalized as only single setting was selected for conducting the study also age group of the study subject was school age i.e., 6 to 12 years and thus not applicable to all paediatric age groups.

Research Highlights

What is the current knowledge?

- Currently there has been no such tool like PAT (Psychological adaption tool) for children.
- While treating the physical symptoms the "psychological adaptation" aspect is often ignored in children who are suffering from chronic illness.

What is new here?

- First structured tool focused on assessing psychological adaptability in children with chronic illness.
- Can be used as a screening tool in pediatric clinics, schools or counselling centers.
- Help identify children with poor adaptability and support them.
- Applicable in pediatric medicine, child psychiatry, psychology and community health.

Conclusion

In conclusion, result of this study has shown that PAT is a feasible, highly reliable and valid tool to measure the psychological adaptation in children with chronic illness and thus can be used to assess the psychological adaptation level. It accords towards the need for further more research into the measurement of the psychological adaptation since it is an important aspect to consider in children who are suffering from the chronic illness. Therefore, by paying attention to the psychological adaptation level doctors and nurses can provide high quality paediatric health care services for children.

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Author's Contribution

Conceptualization: Shivani Singh.
Data curation: Shivani Singh.
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Investigation: Shivani Singh.
Methodology: Shivani Singh, Mukesh Chandra Sharma, Sanjeeta Dara.
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Resources: Mukesh Chandra Sharma, Sanjeeta Dara.
Supervision: Mukesh Chandra Sharma, Sanjeeta Dara.

Validation: Mukesh Chandra Sharma, Sanjeeta Dara.
Visualization: Shivani Singh.
Writing–original draft: Shivani Singh.
Writing–review & editing: Shivani Singh.

Competing Interests
There is no conflict of interest in the study.

Data Availability Statement
The data supporting the findings of this study are available from the corresponding author upon reasonable request.

Ethical Approval
Ethical clearance was obtained from the institutional ethical committee of the with reference number: AIIMS/IEC/2022/4061. Informed written consent was taken from the study subjects after giving proper explanation of the purpose of the study. Confidentiality and anonymity of the subjects and the data collected were maintained throughout the study.

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