Development and Validation of Indigenous Measure of Maternal Tolerance in Children with Autism

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Present study was aimed to develop an indigenous scale which measures the tolerance of mothers having children with autism and to establish the psychometric properties of the measure. This study was conducted in four phases. In the first phase, interviews were conducted with mothers having children with autism, themes were identified and item pool was generated. In the second stage, content validity of the items was established by reviewing it from professionals. Third stage comprised of piolet study, main study and statistical analysis (factor analysis; EFA and CFA). In the fourth stage, psychometric properties of the measure were established. Results indicated good test-retest reliability and convergent validity. This development and validation of this measure has multifold implications as it can be used in future researches and in clinical setting and it can be helpful in devising culture sensitive interventions.

Keywords: Maternal tolerance scale, autism spectrum disorder, psychometric properties[1]

Introduction

The constructs of autism and tolerance are not new concepts. They have been studied since earlier times and a lot of literature can be found regarding both constructs but maternal tolerance in mothers having their

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children diagnosed with autism have scarce literature till date. It is well known fact that families of children with developmental disabilities experience chronic stress (Cetinbakins et al., 2020). Caring for a child with autism puts a lot more pressure on parents rather than the parents of other children. This parenting stress effected the whole family and they could not function on regular coping strategies as they were functioning before (Torbet et al., 2019). Having a child with autism not only cause higher level of stress but it also impacts other family dynamics i.e., marital relationship of parents, sibling's interaction, social circle, satisfying needs of the family, parental coping and interpersonal relationships as a whole. Parents feel isolated from the external world because they are in continuous cycle of parent-child interaction. Parents' life and other responsibilities are also compromised (Choudry, 2020). Recent literature has showed significant stigmatization among parents of child with autism (Alshaigi et al., 2020).

Parents of children with autism reported higher level of agitation and irritability which leads towards destructive parenting interactions and maladaptive communication pattern between parents and their children (Chan & Lam, 2018). Parents became more harsh, less warm and exhibited lower levels of nurturance, support and care. Such negative parenting behaviors served as a model to the children with autism and resulted in poor self-regulation and adverse effects on the mental health and can cause behavioral problems in children (Chan et al., 2022).

Autism spectrum disorder's prevalence is more in the recent decades as compared to in the past and it is receiving significant attention worldwide. Global prevalence indicated 1/100 children diagnosed with autism (Zeidan at al., 2022). Systematic review and meta-analysis suggested its prevalence in Asia as 0.36% (Qiu et al., 2019). In Pakistan alone its prevalence has risen up to as many as 3, 50,000 diagnosed cases of autism in Pakistan as estimated by Pakistan Autism Society and many are left identified or diagnosed because of lack of awareness about neurodiversity in Pakistan (Khalid et al., 2020).

Having a child with autism not only cause higher level of stress and anxiety but it also effected marital relationship of parents, adjustment of the needs of the family and siblings, economic burden, social circle, parental coping and interpersonal relationships (Begum & Mamin, 2019; Choudry, 2020).

Many measures existed which assesses tolerance level in parents i.e., Child Rearing Inventory (2003), Distress tolerance scale (2015), Discomfort Intolerance scale (2005). Despite having a variety of measure, no measure assesses tolerance of mothers regarding autistic status of their child. Child Rearing Inventory have poor psychometric properties, Eyberg Child Behavior Inventory does not measure tolerance rather the discrepancy of its two scale i.e., intensity scale and problem scale generate a measure of tolerance (Colvin, et. al., 1999). Discomfort Intolerance Scale only measures the beliefs underlying tolerance i.e., life should be comfortable, I cannot tolerate any emotional disturbance etc. Distress tolerance scale generally measures an individual capacity to perform functionally in the presence of any kind of distress. The well-being and development of children with autism spectrum disorder (ASD) depend on the support and care they receive from their parents, particularly their mothers. The development of a validated measure of maternal tolerance specific to children with autism is crucial for several reasons. It would provide a standardized tool to assess maternal well-being, identify mothers in need of additional support, evaluate intervention outcomes, and investigate the relationship between maternal tolerance and child outcomes. There is need to develop an indigenous measure of maternal tolerance which measures tolerance level of mothers who have children with autism.

Methods

This research project was conducted in four stages.

Phase 1

In first stage, qualitative inquiry approach was used to interview mothers and to explore their reactions towards the autistic status of their children. 5 mothers were selected to conduct the interviews. Participants were selected from Government and private setups. Participants have education level above matric and they were seeking treatment for their child. Apart from this, all mothers were housewives and were not employed. All of them were Muslims. Time taken for interviews ranges from 15-25 minutes. Interviews were recorded and transcribed. The transcriptions were thoroughly reviewed and common themes reported in all interviews were emerged. Based on the data collected from interviews, item pool of 34 items was generated. These items were cross checked with existing literature and data gathered from interviews.

Phase 2

The items developed from interviews were reviewed by the 5 experts. 3 of them were clinical psychologist working with child and 2 of them were experts working in special education institutes. Experts were asked to review the items on a scale of 1-10 on the basis of their relevancy to the construct. After review from the experts, 3 items were discarded, 5 items were merged into 2 items and Item 1, 7, 8, 13, 14, 18, 20, 23, and 25 were rephrased. After modifying the items, measure of 24 items was finalized. Format of the measure was decided to be 5-point Likert scale, with score ranging from 0-4 whereas 0=completely agree and 4=completely disagree. Total score ranges from 0-124, with higher score indicating high maternal tolerance.

Phase 3

Permissions were sought from respective departments and authors. Piolet study was conducted with 20 participants. Then the main study was conducted and data was analyzed.

Phase 4

Test-retest reliability and convergent validity was established for the indigenous measure of maternal tolerance.

Participants

Non probability purposive sampling strategy was employed to recruit sample. Total sample of 380 participants (Mage=32.2, SD=6.5) were recruited. Sample of 250 for Exploratory Factor Analysis and sample of 130 for Confirmatory Factor Analysis. Sample was recruited from governmental and private institutes and online data was also gathered from autism groups in Pakistan i.e., Autism Resource Group Pakistan, Autism Resource Group Peshawar and Autism Family support group and Autism Awareness group.

Participants selected were those whose child is diagnosed with autism and the age of the children should be in the range of 3-12 and mothers having any kind of psychiatric problem were discarded. Single mothers and mothers with second marriages were also discarded.

Measures

Demographic sheet. Demographic sheet consists of two types of questions. One part deal directly with demographic related variables (age, education, income, religion, occupation, family system and general home environment) while other questions are basically related to the inclusion and exclusion criteria and some additional

questions were added i.e., caretaker of child, time spent with child daily, perceived difficulty of child behavior, and coping with stressful situations.

Mental Health Screening Quesionnaire (Najeeb & Kausar, 2010). It is a screening measure based on the main features of psychiatric illnesses described in ICD-10 and DSM-IV-TR. It has five items in total and each item measure a specific pathology. Its score ranges from 0-4. Higher scores mean presence of pathology while score of 1 and below indicates no pathology.

Indigenous measure on Maternal tolerance of children with autism. This questionnaire consists of 25 items measuring Maternal tolerance of mothers having children with autism. It is a 5-point Likert scale, with score ranging from 0-4 whereas 0=completely agree and 4=completely disagree. Total score ranges from 0-124, with higher score indicating higher maternal tolerance. Items are usually regarding how mother is reacting towards disruptive behavior of her child i.e., I get annoyed, due to my child's condition, I have problems in life, I slapped him, I feel ashamed when he annoyed me in public etc.

Distress Tolerance Scale (Simons & Gaher, 2005). It is a 15-item self-report scale to evaluate individual's emotional distress tolerance. It consists of four subscales: absorption in one's stressful emotions (e.g., "My feelings of distress are so intense they completely take over"), tolerance of upsetting emotions (e.g., Feeling distressed or upset is unbearable to me"), appraisal of capacity and distress experienced (e.g., "I can tolerate being distressed or upset as well as most people"), emotional regulation (e.g., "I will do anything to avoid feeling distressed or upset"). It is a 5-point Likert scale, with scores ranging from1-5 (where, 1= strongly agree to 5= strongly disagree). Low scores indicate low distress tolerance while high scores mean high ability to tolerate distress.

Procedure. Permission from Departmental Ethical Research committee was taken. Permissions were taken from respective authors of the psychological measures used. Sample was selected through purposive sampling from Children Hospital, Learning Institute for Slow Learners and Shadab Training Institute for Special Education. Permissions were also taken from the respective institutes. Permissions were also taken from participants.

In the pilot study 10 mothers were taken as sample. Data was obtained from them and mothers were asked to give feedback regarding the difficulty of items on maternal tolerance measure, how well the items convey their meaning and the comprehensiveness of the items.

During the main study, total sample of 380 was employed. Initially a sample of 280 was approached, however 263 met the criteria of inclusion/exclusion and 250 participants completed the research questionnaires with the response rate of 89.2%. Participants were informed about the objective of the research and voluntary participation was ensured by taking consent of the participants. Confidentiality was assured and participants were told about their right to withdraw from study. All ethical considerations were considered while gathering data. Exploratory Factor Analysis (EFA) was conducted on the gathered data, finalizing the factor structure of the measure and its items. After EFA, data of 130 was gathered again to confirm the prior obtained factor structure by conducting Confirmatory Factor Analysis (CFA).

Results.

Exploratory Factor Analysis

Principal Component Analysis for 25 items was done through varimax rotation. Kaiser criteria of was employed to retain factors having eigenvalue greater than 1 (Kaiser, 1960). Furthermore, the results of Cattell's Scree test also indicated the number of factors to be retained were 5. Kaiser-Meyer-Olkins and Barlett's test of sphericity was run which indicated that sample was adequate (>.5 as per Field, 2018) and have significant correlation matrix.

Table 1

KMO and Bartlett's Test Result.

Kaiser-Meyer Olkin measure of Sampling Adequacy		.78
Bartlett's test of Sphericity	Approx. Chi-square	826.54
	Df	300
	Sig.	.000

Factor analysis with 5 factors and suppression of .4 was run on the data. All the items had factor loading above .4. Item 6, 13, 18 and 25 does not load on any factor so, these items were discarded. 18 items were finalized accounting for 66.49% of variance.

Table 2

Results from Exploratory Factor Analysis of Indigenous Measure on Maternal Tolerance (MT) of Children with Autism.

Items	Factor loadings			
	1	2	3	4
Item 8	.59			
Item 10	.68			
Item 11	.72			
Item 12	.74			
Item 19	.71			
Item 2		.79		
Item 4		.50		
Item 5		.49		
Item 9		.77		
Item 16		.57		
Item 1			.76	
Item 7 (R)			.54	
Item 17 (R)			.92	
Item 21 (R)			.83	
Item 14				-.63
Item 24				.62
Item 20				.46
Item 23				.69

Note: R indicates reverse scored items.

18 items were finalized accounting for 66.49% of variance.
Reliability analysis was run on the data and a reliability of .74 was
calculated. Pearson product-moment correlation analysis was also run to
analyze the inter-item correlation.

Table 3

Items Retained in each Factor, Variance and Eigenvalue.

Factors	Items Retained	No. of items	Variance (%)	Eigenvalue
1	8, 10, 11, 12, 19	5	17.7	3.85
2	2, 4, 5, 9, 16	5	26.3	3.77
3	1, 7, 17, 21	4	12.2	1.98

| 4 | 14, 20, 23, 24 | 4 | 10.2 | 2.86 |

Thematic analysis suggested factor 1 as 'Social approval & Belief about Tolerance', factor 2 as 'Tolerance of Child's Disruptive Behavior', factor 3 AS 'Negative appraisal' and factor 4 as 'Positive coping skills'. Cronbach alpha value for each factor was calculated indicating Inter-factor correlations.

Table 4

Cronbach's Alpha and No. of Items

Factors	Cronbach's α	No. of Items
Social approval & Belief about Tolerance (F1)	.77	5
Tolerance of Child's Disruptive Behavior (F2)	. 72	5
Negative Appraisal (F3)	.67	4
Positive Coping Skills (F4)	.63	4

A measure of 18 items with 4 factors was finalized. All the factors utilized 5-point Likert scale, with score ranging from 0-4 whereas 0=completely agree and 4=completely disagree whereas, higher score indicating higher maternal tolerance.

Confirmatory Factor Analysis

Confirmatory Factor Analysis (CFA) was done through AMOS to confirm the factors included in the indigenous measure of Maternal Tolerance (MTS). The model for confirmatory factor analysis is given below.
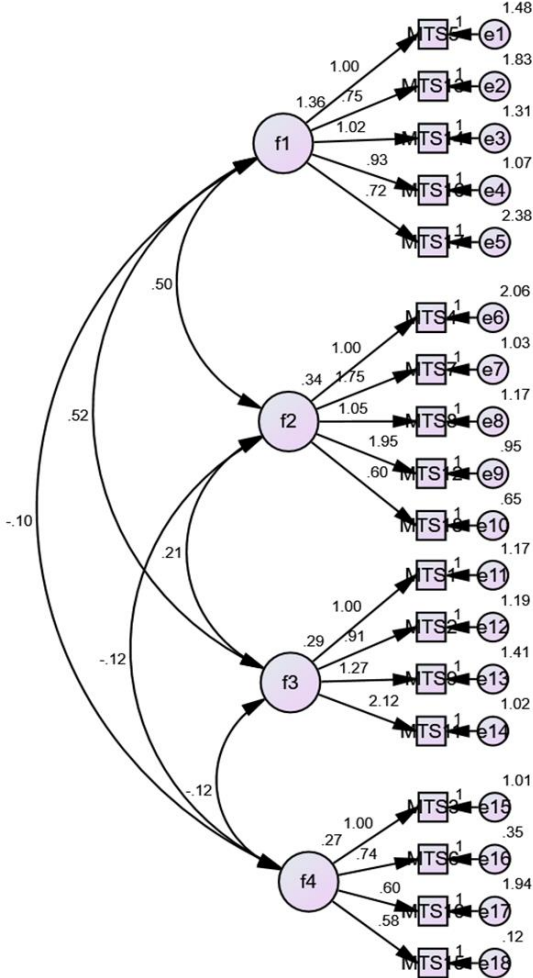
Fig 1: Hypothesized Model as suggested by EFA

Table 5
Goodness-of- fit Indices for Model

Model	χ2	df	NFI	CFI	RMSEA
MTS	1.6	1.6	.79	.84	.079

The results of present study revealed that χ2 is 1.6 and studies demonstrated chi square less than 3 and RMSEA between 0.05 and 0.08 is considered to be good (Portela, 2012)

RMSEA < .08 is acceptable and above table showed a value of .079. Present data revealed CFI value of .81 which also makes the three assumptions acceptable. Thus, goodness of fit model is satisfied.

Test-Retest Reliability Analysis

For Test-Retest Reliability, a number of 40 participants from the sample were asked to fill the questionnaire again after a gap of 10-14 days. Statistical Package for Social sciences was used to analyze the data for test-retest reliability Pearson product Correlation was used to calculate correlation between scores of test and retest of the factors of MTS. The following table contains analysis of data obtained for the test and re- test of the indigenous measure of Maternal Tolerance (MTS) and the reliability analysis of the total scores of subscales of MTS was used.

Table 6
Pearson Product Moment Correlation between Test and Retest Score on Factors of Indigenous Measure of Maternal tolerance

Factors	R
	Test-Retest
Social Approval & Belief about Tolerance (F1)	.967***

Tolerance of Child's Disruptive Behavior (F2)	.700***
Negative Appraisal (F3)	.945***
Positive Coping Skills (F4)	.976***

Note P<.001

Results show high correlation of .9 that concludes the indigenous measure of MTS is highly reliable.

Convergent Validity

For this purpose, a standardized measure of Distress Tolerance Scale (DTS) having 15 items is used to conclude that the indigenous measure of maternal tolerance (MTS) correlates with the other measure of Distress Tolerance Scale (DTS) because they both assess the same construct. The following table shows the correlation between both measures of MTS and DTS. Statistical Package for Social Sciences (SPSS) is used to explore the convergent validity.

Table 7

Correlation between Total Score of indigenous measure of Maternal Tolerance (MTS) and Total Scores of Distress Tolerance Scale (DTS)

Scales	R	M	SD
MTS	.70	53.8	11.6
DTS		56.9	11.3

Results indicate there exists high correlation between both constructs. Convergent validity is obtained as .70 and studies suggested that R>.60 is considered moderate (Rovers, 2016).

Discussion

Researchers have operationally defined maternal tolerance as tolerance of child's disruptive, and inattentive behavior (Breston et al., 2003) and some researchers conceptualize it as maternal view of unpleasantness and nuisance, punitive attitude, and understanding child condition (Morgan & Young, 1975). But maternal tolerance of mothers having child with autism receives very little attention till date.so, the

present study aims to develop an indigenous measure on maternal tolerance of children with autism.

Community sample of 380 was recruited as participants. Mean age of mothers was 32.2 with SD=6.5. Most of the mothers reported having nuclear system (60.2%). 21% of mothers reported having any physical complaints like high blood pressure, coronary heart diseases, or diabetes. Most of the mothers' reaction towards problematic child behavior was educating the child (41.3%) whether the behavior he/she display was appropriate or not, while some just put up with it and bear it (27.5%). 29.3% mothers reported that they either beat or scold their child whenever he/she engages in disruptive behavior. Most of the mothers reported having religious inclination above 5 on a scale of 0-10 where 0=not inclined at all and 10=very much inclined.

Results of factor analysis indicated a measure with 4 factors and 18 items. Factor 1 consisted of item 8, 10, 11, 12, 19 and it was named as 'Social approval and beliefs about tolerance'. Results of factor analysis are found to be consistent with the data gathered from interviews. Items in Factor 1 are related to fear of other people opinions i.e., Item 5 & 17 (I feel ashamed when the child annoy me in front of relatives and guests, I don't go to places where people mock my child) and beliefs that mother held about the condition of her child i.e., Item 16 (Facing my child condition is very difficult for me) and thoughts as in Item 13 & 14 (I think life should be easy, I have problems in my life because of my child condition) . Results of factor analysis are found to be in consistent with the data gathered from questionnaire. It is supported by researches that problematic behavior of autistic child can cause distress in parents (Yorke, 2018). Mothers also reported they are unable to attend various events because when they went to crowded places, it triggers the child and the child becomes hyper (smashing, throwing different things and shouting over others). Therefore, such social circumstances cause distress among mothers (Bopaeda, 2021).

Factor 2 was named as Tolerance of Child's Disruptive Behavior (F2). Items in Factor 2 are related to irritability and annoyance caused by child's disruptive behavior and various consequences related to it as in Item 7, 8, and 12 (I get annoy by child's behavior, I scold the child, if child does something wrong, and I get angry if child doesn't follow routine). Annoyance and scolding are the result of child's behavior. It is supported by the researches that caregiver have sensitivity to child's disruptive behavior that can cause physiological arousal in caregivers (Leerkes, 2016). In item 4, 18 (It is difficult to handle the child when child shows stubborn behavior, I lock the child when I have more work to do). The

difficulty in dealing with ASD child behaviors requires a special training to avoid such consequences of scolding and isolating the child. This can have adverse effects on the child. Researches indicate that parent need guidance about related experiences while rearing a child with ASD (Dieleman et al., 2018).

Factor 3 was named as Negative appraisal. This factor is majorly related to mother's intolerance and different sensitivities in child with ASD. The Item 2 (I reprimand/ slap the child when child doesn't eat food) not only predicts mother's intolerance but also highlights the food sensitivity. Research showed that child with ASD develops different sensory sensitivities including taste (Jing, 2018). Mothers also reported that child is fixated at one food and not eat other nutritious food for a fixed duration of week.

The other items 1, 9, 11 (I slap the child when the child disobeys, I shake the child hardly, I get tired of educating the child same thing again). Item 11 indicates low intellectual functioning of child with ASD, as the mother has to repeat the instructions. It is supported by different researches that there occur developmental trajectories in child with ASD (Canitano et al., 2020). Studies indicate that mothers having children with Autism also face different exhaustion stages that results in such consequences of slapping the child and being tired of tolerating (Kutuk, 2021).

Factor 4 was named as Positive Coping Skills and it consists of item 3, 6, 10, 15. All these items are related to positive coping skills of mothers to deal with ASD child. As in Item 3, 6, 15 (I gave child his favorite things to draw child's attention, I divert child's attention if child exhibit irritable behavior, I consider my child as blessing from Allah), all these statement infer different coping skills e.g., attention-diversion, reinforcement and positive thinking. All such coping statements also impacts quality of life. Moreover, in the present study mothers also reported such positive and optimistic statements keep them going (Ni'matuzahroh et al., 2021).

Test-Retest reliability also showed a correlation of 0.9 that shows the indigenous measure has good test-retest reliability. Various studies reported correlation value of .7 to be a satisfactory reliability. A gap of 10-15 days is considered enough for test and retest. (Keszei et al., 2010)

Construct validity was also calculated and .70 value is obtained. The standardized Distress Tolerance Scale and indigenous measure of Maternal Tolerance show moderate validity and infers that both the scales measure what they claim to measure (Rovers, 2016).

Conclusion

Present study developed and validated a measure of maternal tolerance of those mothers having their children diagnosed with autism. Result of factor analysis and its psychometric properties suggested the tool to be a reliable and valid measure which can be employed in clinical setting as well as for academic purposes.

Limitations and Suggestions

Every research has some limitations which provides us with guidelines to further work upon. As, the current study was an academic project which had some time constraints due to which the size of sample selected for test-retest reliability was 40 participants whereas, some authors recommended using a sample size of 100 (Kline, 2000). So, the measure could have shown more reliable results if larger sample would be used. Furthermore, split half reliability, criterion validity and divergent validity of the measure could be established in the future studies.

Future Implications

This study will serve as an essential element while understanding the impact of autism on the caregiver and the family as a unit and while devising family-based interventions. By assessing and monitoring maternal tolerance levels over time, professionals can tailor interventions to address specific challenges faced by mothers of children with autism. This targeted support can help mothers build coping strategies, enhance their resilience, and promote adaptive parenting practices. By using such a scale, researchers and clinicians can measure changes in maternal tolerance levels following intervention programs, enabling them to assess the impact and modify strategies as needed. By measuring maternal tolerance, researchers can investigate the association between maternal tolerance levels and child outcomes, providing insights into the mechanisms through which maternal behaviors influence child development

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