ISSN E: 3006-1466
ISSN P: 3006-1458
CONTEMPORARY JOURNAL OF SOCIAL SCIENCE REVIEW
CJSSR
CONTEMPORARY JOURNAL OF SOCIAL SCIENCE REVIEW
Vol.03 No.04 (2025)

DEVELOPMENT AND VALIDATION OF TOOL FOR ACTIVATION OF MOTHERS WITH CHILDREN HAVING AUTISM SPECTRUM DISORDER

Fareeha Latif Randhawa*[1], Dr. Amna Khawar[2]
[1]Principal Clinical Psychologist, University of Child Health Sciences, The Children Hospital,
Lahore, Pakistan.
Email: fareelatif@gmail.com
[2]Assistant Professor, Lahore College For Women University, Lahore, Pakistan.
Email: Aamnakhawar786@gmai.com
**Corresponding Email: fareelatif@gmail.com*

Abstract
Objective: *To develop and validate an indigenous tool to measure activation in mothers having children with ASD in Pakistan.*
Study Design: *A mixed-method approach with two phases, first phase involved qualitative item generation and content validation, followed by exploratory factor analysis. Second phase focused on confirmatory factor analysis and validation.*
Place and Duration: *Study was conducted in Lahore, Pakistan, with data collected from February to November 2023.*
Materials and Method: *Phase 1 generated 84 items through literature review, six semi-structured interviews, and two focus groups.11 items removed due to repetition. Content validity was assessed by six experts, retaining 57 items with a CVI ≥ .83 and high. EFA was performed on 316 mothers (aged 21–40 years) with children aged 3–12 years diagnosed with mild to moderate ASD. Phase 2 validated the tool using CFA on 204 mothers.*
Results: *EFA confirmed a two-factor structure, explaining 20.87% of variance. CFA showed acceptable model fit (CMIN/DF = 1.59, CFI = .91, TLI = .90, RMSEA = .05). The final 28-item Tool for Activation of Mothers (TAOM) comprised two factors i.e. Maternal Attributes (21 items) and Resilience activation (7 items).*
Conclusion: *The tool for activation of mothers is a reliable and valid instrument for assessing maternal activation in managing ASD child in Pakistan. It supports family-centered approaches, empowering mothers to reduce dependence on mental health services and improve child outcomes*
Keywords*: maternal activation, autism spectrum disorder, resilience activation, maternal attributes*

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder and it impairs the social emotional reciprocity, social interaction and marked by stereotypic movements in the child (American Psychiatric Association, 2022). The current estimates from the Centers for Disease Control and Prevention (CDC) showed that the prevalence of autism is 1 in 31 children aged 8 years in the United States and boys had three times more chances of getting autism than girls (Shaw.,2025). Whereas, in Pakistan the prevalence of autism is 1 in 150 children (Bashir et al., 2020). Diagnosis of autism usually come up with multiple challenges ranging from acceptance, coping with social stigma, facing the everyday challenges, getting appropriate services for the child, dealing with financial burden and comorbidities and lack of sufficient professional assistance (Appah et al., 2024) Parenting a child with ASD is very challenging in most countries where support is limited (Ijaz et al., 2021;Trew, 2024). Recent studies also found significant

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negative impact on psychological wellbeing leading to elevated stress and higher prevalence of anxiety and depression among parents of ASD (Battanta et al.,2024)). Similarly, parenting an ASD child in Pakistan leads to more stress and strained social relationships. According to research, mothers usually face more psychological issues than fathers ((Nadeem et al., 2024) including managing household, financial struggles and work life balance.

In subcontinent mother's role is primary in care giving, as they spend extended time with their children (McAuliffe et al., 2022.), their activation in managing ASD becomes paramount. Activation means "to make active or capable of action" (Collins, 2019). Activation is a relatively new term being used with parents and care givers of children with developmental disabilities especially autism spectrum disorder by helping them to increase their information, enhancing their skills and abilities and boosting their confidence to play active role in their child intervention (Mirza et al., 2016.).In west activation research was initially limited to physical health but it was later broadened to chronic conditions and ASD, yielding positive outcomes (Ruble et al., 2019.) and this was the inspiration for the development of current scale.

As the prevalence of autism is on rise worldwide and parents of ASD children usually report difficulty in obtaining timely and quality services (Smith-Young et al., 2020.), hence parent centered interventions are proved to be successful. Earlier interventions based on training of parents for management of ASD come up with good results in high income countries (Ijaz et al., 2021). In Pakistan parent mediated intervention for ASD was used first time in 2016. (Ijaz et al., 2021). Parental involvement and training is of great significance as it equips and enhances the parental skills to manage challenging behaviors and child growth

Pakistan, a third world country with limited resources, struggles in providing sufficient rehabilitation services for neurodevelopmental disorders (Azeem et al., 2021;Latif et al., 2025.)Few large government hospitals in major cities offer services for such children, which are insufficient for the country's vast population. This situation is further compounded by limited public awareness about autism, as evidenced by a study where 5 out of 15 mothers hadn't heard of autism before their child's diagnosis (Furrukh & Anjum, 2020). However, social media has emerged as a valuable medium for educating parents about neurodevelopmental conditions, potentially contributing to the rise in early diagnoses. With the effectiveness of family focused approaches there is need to assess and empower mothers to take active role in the rehabilitation of children. With the effectiveness of family focused approaches there is need to assess and empower mothers to take active role in the rehabilitation of children with ASD in Pakistan.

Thus, there is a need to access mother activation, for this purpose present study developed a unique, culturally-relevant, two-dimensional tool to assess the attributes necessary for the active participation of mothers in the management of children with ASD. By assessing and then empowering mothers to get more engaged in their child's care, positive outcomes leading to reduced dependence on professional services, alleviating provider burden, promoting positive child development outcomes through effective management of core symptoms and challenging behaviors and better psychological well-being. Considering mothers' attributes and resilience in overcoming the barriers specific to ASD care can enhance the activation.

Objectives of the study

- To develop and validate an indigenous tool for measuring the activation of mothers having children with autism spectrum disorder

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Methodology

This study comprised of mixed method approach by using qualitative and quantitative research designs. Study is conducted in two phases. In Phase 1 the tool was developed by reviewing previous literature, semi structured interviews and focus groups and was carried out by qualitative research design. Moreover, quantitative research approaches such as mean, standard deviation, content validity, chronbach alpha reliabilities; exploratory factor analysis and confirmatory factor analysis were used to establish standardization and factor analysis of tool of activation of mothers of ASD children.

Item were generated through reviewing the existing and previous literature. Six semi structured interviews were done with professionals dealing with ASD children, including clinical psychologists, speech therapists, developmental pediatricians, and special needs educationists. The two focus group (n=7) involved mothers of ASD children diagnosed between 3 and 12 years old, who were asked questions based on the interview guide.

The interviews were analyzed using interpretative phenomenological analysis (IPA). The primary researcher initiated the analysis, which was assessed by a PhD in psychology. The analysis resulted in a master table of themes among cases, aided by verbatim excerpts from each interview transcript.

Initially 84 items were generated from which 11 items were removed based on repetition and clarity. 73 items were then given to six experts. After content validity 16 items with CVI below .83 were removed. Only 57 items having CVI of .83 and above were retained. A pilot study was conducted with 57 items on (n=30) mothers with ASD children, finding clarity and relevance in the content of the tool.

Results

Exploratory Factor Analysis

An Exploratory factor analysis (EFA) was done on 316 participants. Kaiser-Meyer Olkin (KMO) and Bartlett's Test of Sphericity were used to assess the sampling adequacy and data-set suitability. The correlation coefficients and partial correlation coefficients were compared, and it was found that KMO value was 79% (.79) that was greater than .50 and Bartlett's test is calculated as .00 i.e. < .50. Therefore, based on the findings from KMO and BTS, the data-set was suitable for performing EFA.

Table 1

*Communalities for Exploratory Factor Analysis of a Tool for Activation of Mothers (*N = *316).*

Sr no.	Item no.	Communalities	Sr no.	Item no.	Communalities
1.	TAoM2	.51	31.	TAoM43	.61
2.	TAoM4	.32	32.	TAoM44	.46
3.	TAoM6	.46	33.	TAoM45	.54
4.	TAoM7	.42	34.	TAoM46	.65
5.	TAoM8	.61	35.	TAoM47	.16
6.	TAoM9	.62	36.	TAoM48	.44
7.	TAoM11	.20	37.	TAoM49	.36
8.	TAoM14	.38	38.	TAoM50	.47
9.	TAoM15	.44	39.	TAoM51	.60
10.	TAoM16	.58	40.	TAoM52	.45
11.	TAoM18	.31	41.	TAoM53	.48
12.	TAoM19	.21	42.	TAoM54	.44

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13.	TAoM20	.27	43.	TAoM55	.08
14.	TAoM21	.40	44.	TAoM56	.53
15.	TAoM23	.39	45.	TAoM57	.53
16.	TAoM24	.57	46.	TAoM58	.49
17.	TAoM25	.48	47.	TAoM59	.52
18.	TAoM26	.37	48.	TAoM60	.60
19.	TAoM27	.30	49.	TAoM61	.56
20.	TAoM28	.33	50.	TAoM62	.35
21.	TAoM29	.43	51.	TAoM63	.60
22.	TAoM31	.50	52.	TAoM64	.56
23.	TAoM32	.52	53.	TAoM65	.49
24.	TAoM35	.21	54.	TAoM66	.28
25.	TAoM36	.51	55.	TAoM67	.18
26.	TAoM37	.45	56.	TAoM68	.35
27.	TAoM39	.55	57.	TAoM69	.46
28.	TAoM40	.46			
29.	TAoM41	.49			
30.	TAoM42	.45			

The principal axis Factoring method with the oblique rotation method was used as it was assumed that factors would likely be related conceptually. Results found that Communalities ranged from .08 to .61. Scree plot (see fig.1) showed that three factors were significant. Eigenvalues of ≥1 was used to interpret the number of factors in the data set.

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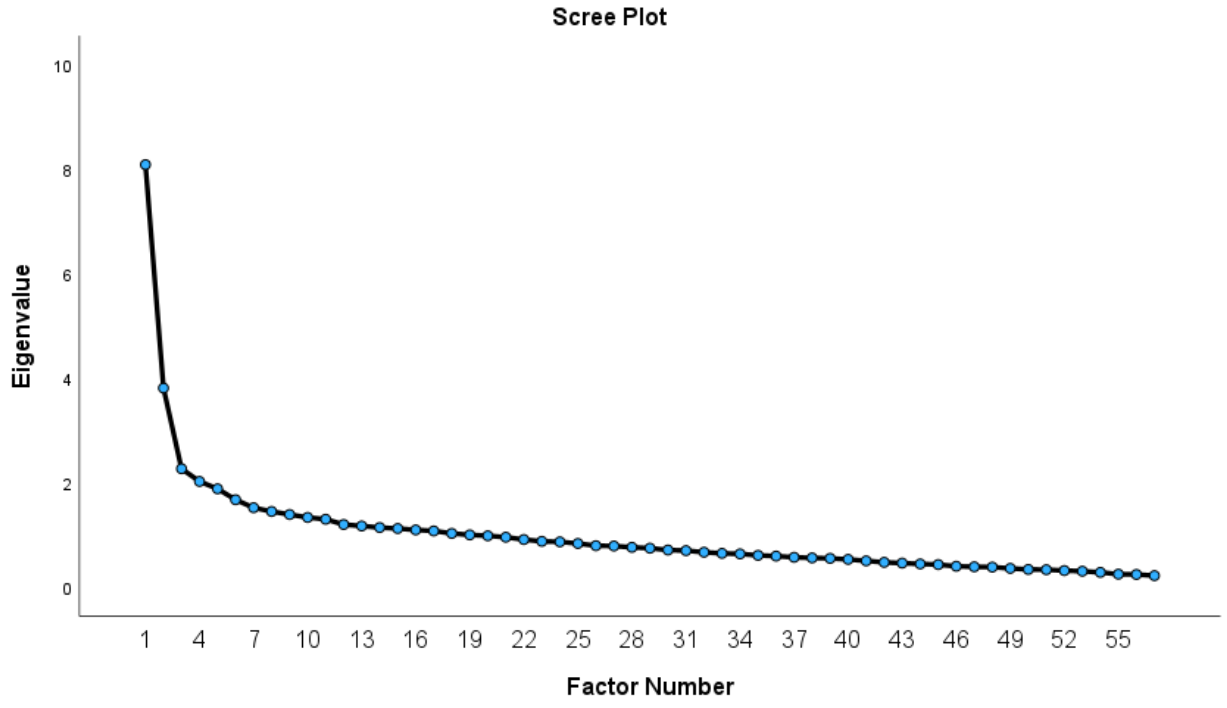

Figure 1. Scree Plot for Exploratory Factor Tool for Activation of Mother Scale ($N = 316$).

Factor loadings are considered as one of the important values in EFA. Stevens (2002; cited in Field, 2009) suggested that values explaining 16% of total variance and having factor loadings greater than .30 should be taken into consideration during factor analysis.

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Table 2

Factor Loadings, Eigen Values for Exploratory Factor Analysis, Varimax with Kaiser Normalization of Tool for Activation of Mothers (N=316)

		Factors	
No.	Items	1	2
1.	TAoM64	.63	
2.	TAoM60	.61	
3.	TAoM63	.60	
4.	TAoM56	.58	
5.	TAoM61	.56	
6.	TAoM43	.56	
7.	TAoM42	.55	
8.	TAoM25	.52	
9.	TAoM57	.51	
10.	TAoM41	.50	
11.	TAoM40	.50	
12.	TAoM39	.50	
13.	TAoM58	.49	
14.	TAoM50	.49	
15.	TAoM68	.47	
16.	TAoM32	.46	
17.	TAoM65	.45	
18.	TAoM53	.41	
19.	TAoM52	.39	
20.	TAoM7	.39	
21.	TAoM45	.38	
22.	TAoM62	.38	
23.	TAoM48		.49
24.	TAoM21		.47
25.	TAoM15		.46
26.	TAoM14		.46
27.	TAoM26		.41
28.	TAoM29		.40
29.	TAoM16		.38
	Eigenvalues total	8.08	3.81
	% of Variance	14.18	6.68
	Cumulative %	14.18	20.87

Extraction Method: Principal Axis Factoring.
Rotation Method: Direct Oblimin with Kaiser Normalization.

Factor loadings above .38 were retained (Field, 2009) and with a factor loading under it were excluded from the scale, a total of 28 items were removed. Initially three factors were extracted but the third factor, mother attitude was dropped, as the items in that factor were giving same meaning as factor 1 (mother attribution). Also, several items that had low loading. As a result

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of the EFA, the scale had a two-factor structure that consisted of 29 items. There are 22 items under the maternal attributes factor and 7 items in activation resilience factor.

Factor 1 (Maternal Attributes)

Factor 1 contained 22 items (68, 42, 41, 63, 64, 58, 7, 43, 25, 61, 65, 62, 60, 57, 56, 53, 50, 45, 39, 40, 52 & 32) it measures maternal attributes i.e. her belief, information regarding diagnosis and her confidence in her own ability

Factor 2 (Resilience Activation)

Factor 2 contained 7 items (items 14, 15, 16, 21, 26, 29 & 48) and is named as resilience activation in which mother utilizes their inner strength and external support to overcome the barriers for better outcome of their ASD Child.

Scoring

Scale was rated on five-point Linkert scale (1= completely disagree and 5= completely agree). Items were sum scored after reversing the negatively worded items (items no. 48, 21, 15, 14, 26, 29 and 16) of resilience activation factor. Higher scores showed greater mother activation, and low score indicates low mother activation.

Confirmatory Factor Analysis

A confirmatory factor analysis (CFA) was done on 204 participants to make sure that the EFA results were correct and confirmed.

Table 3 shows the fit indexes that were used for the analysis as well as the output values that were made for the data analysis. One item with a low loading was removed and the final model after modification was fitted on 28 items.

Table 3

Model fit Indices for Mother Activation Scale (N = 204)

Model	CMIN/DF	P	CFI	TLI	RMSEA	90% RMSEA CI
Final model	544.21/341=1.59	.00	.91	.90	.05	[.04,.06]

Note. CMIN/DF (Chi-square divided by Degree of Freedom), P-value (Likelihood Ratio), CFI (Comparative Fit Index), TLI (Tucker-Lewis Index), RMSEA (Root Mean Square Error of Approximation)

The model fit indices were in acceptable ranges thus, proves that the scale is adequate. The CMIN/DF values is 1.59 (i.e. ≤ 3). CFI and TLI values also showed acceptable model fit values of .91 and .90 respectively. The RMSEA had value of 0.05 i.e in between 0.03-0.08 (figure 2).

CFA Model

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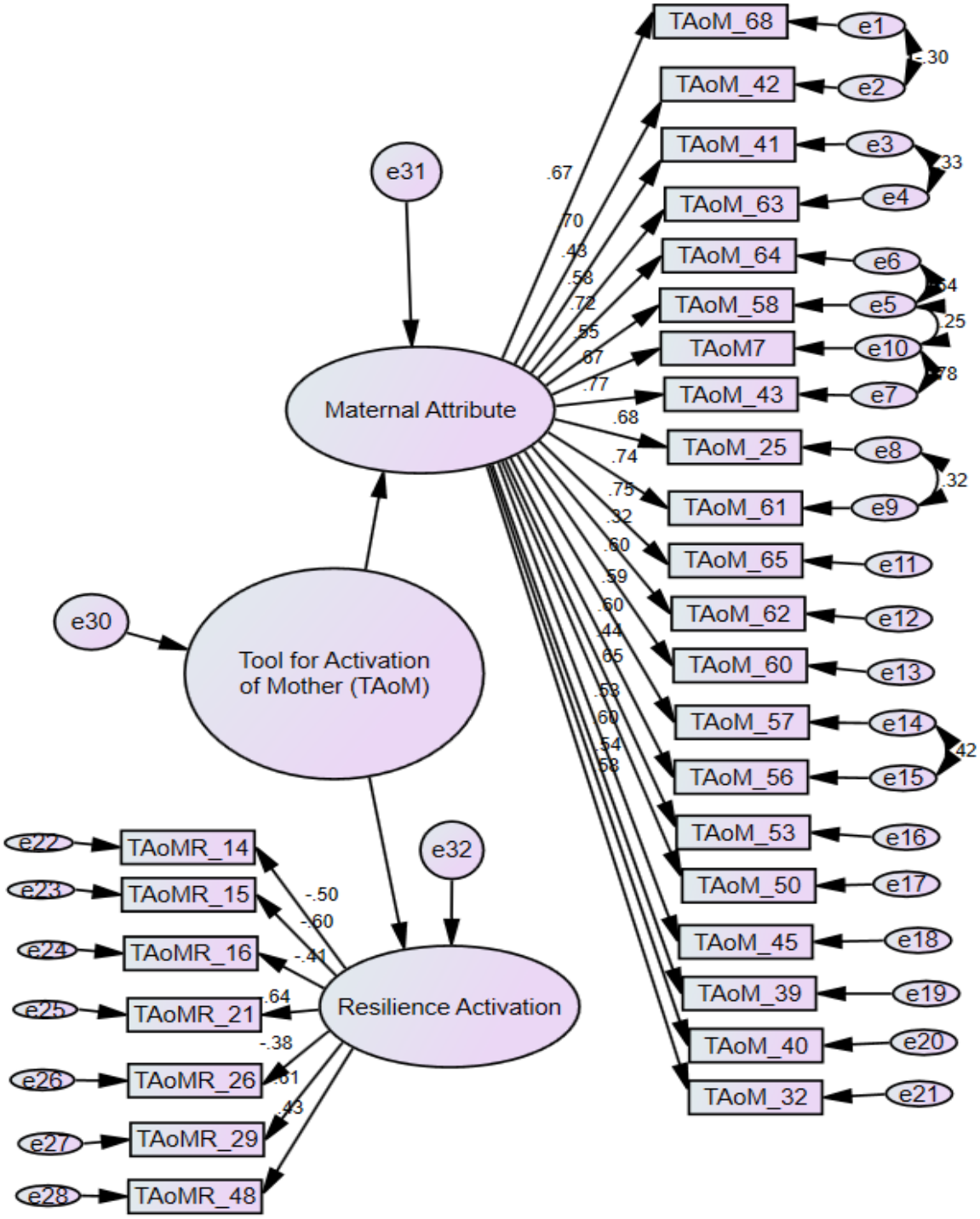

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Discussion

The current study was conducted to develop an indigenous tool to measure the activation among mothers having children with Autism spectrum disorder. The final scale version retained items subdivided in two sub factors i.e. “Maternal attributes” and “resilience activation”. Results demonstrated acceptable internal consistency of the both factors

Maternal attributes comprised of 21 statements measuring the information about the problems of child and significance of therapy and rehabilitation, abilities required to avail the services required for the child and motivation of mothers that help them to take active role in the management of their children.

Second factor was resilience activation comprised of 7 statements relating to the realization of inner strengths and making use of them while working with ASD children. This factor signifies the resilience faced by Pakistani mothers in their cultural context, while taking care of their ASD child.

Parenting a child having ASD is not an easy task, it always comes up with multiple challenges in personal, interpersonal, social, psychological, financial, wellbeing and child related domains (Ramzan et al., 2022). Existing clinical evidences and theoretical background highlighted that parent behavior training programs are effective for children with developmental disabilities as parents learn new strategies and are generally satisfied with such programs ((Chaidi & Drigas, 2020)). Parental involvement brings holistic change i.e. social, emotional and psychological in a child with ASD (Fernández Cerero et al., 2024.).

The present scale, inspired by the PAM-DD, measures maternal attributes and resilience activation in Pakistan, a low-middle income society, where challenges become more escalating. The scale is unique as it considers the sociocultural framework, unlike the nuclear system in the West. Pakistani extended families influence family decisions, and decisions are usually taken by elders or grandparent (Minhas & Isran, 2015). Moreover, as compared to west society, people in Pakistan are less sensitized to children with developmental disabilities and their families (Jansen-van Vuuren & Aldersey, 2020), making coping more difficult due to the sociocultural framework.This highlights the need for a more comprehensive approach to understanding and addressing the unique challenges faced by individuals with developmental disabilities.

Based on these findings an indigenous, culturally sensitive tool was developed in Urdu to measure the activation in mothers. Activation is a relatively new construct in Pakistan. Earlier Self-efficacy and Parental sense of competence of mothers having children with developmental disabilities were being studied.

The study has several limitation as well as this study only conducted on mother and fathers were not catered in the sample, future study need to include fathers in the next study so activated fathers may replace mothers in the time of emergency, i.e, birth of a sibling, death within the family. Secondly the tool’s development in Urdu may limit its applicability to non-Urdu-speaking populations within Pakistan, necessitating further validation in other regional languages.

Conclusion

In conclusion, the development and validation of the Tool for Activation of Mothers (TAoM) having ASD children provides a valuable instrument for assessing maternal characteristics required in empowering mothers for the management of core and challenging behaviors of ASD. This will ultimately lead to less burden on mental health professionals, positive outcomes of management interventions and better psychological wellbeing

Acknowledgments,

Authors acknowledged the contribution of all parents and family who took part in this study

Finical disclosure

The author has received no research grant or finical support to disclose

Conflict of interest,

Authors had no conflict of interest to disclose

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