

RELATIONSHIP BETWEEN PERCEIVED COMMUNITY STIGMA, THE QUALITY OF MOTHER-CHILD RELATIONSHIP AND BURNOUT AMONG MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER RECEIVING SERVICES IN PRIVATE AUTISM CENTERS IN LAHORE, PAKISTAN

Waseem Hussain ^{a*}, & Alishba Malik ^b

^a Student, Department of Clinical psychology, The Superior University, Lahore, Pakistan. Email: su94-mscpw-f24-011@superior.edu.pk

^b Lecturer, Department of Clinical Psychology, The Superior University, Lahore, Pakistan. Email: alishba.malik@superior.edu.pk

*Correspondence to: Ms. Waseem Hussain, Student, Department of Clinical psychology, The Superior University, Lahore, Pakistan.
Email: su94-mscpw-f24-011@superior.edu.pk

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ABSTRACT

Parents are usually the primary caregivers of children with ASD, and their care is challenging. While caring for the child with ASD, they also have to deal with stigma and incorrect perceptions from society, which may cause them to become exhausted and impact their relationship with their child. The purpose of the current research was to investigate relations between parents' perceived community stigma, the quality of mother child relationship and burnout among mothers of children with autism spectrum disorder receiving services in private autism centers in Lahore, Pakistan. It used a quantitative correlational research method to investigate correlations. Sample of 300 mothers of children with ASD were drawn through convenience sampling method from private autism centers of Lahore. The mothers completed provided demographic information form, Parent Perceptions of Community ASD Stigma Scale, The Parental Burnout Assessment and Child-Parent Relationship Scale. The data were analyzed through SPSS Version 27. The analysis conducted is reliability, descriptive statistics, Pearson product moment correlation and linear regression. There was a significant negative correlation between parental burnout and parent-child relationship and between perceived stigma in the community and parent child relationship. Also, community stigma was positively correlated with parental burnout. Linear regression analyses revealed that parental burnout and perceived community stigma were predicting variables of the quality of parent child relationship. These two variables account for variation of the quality of parent child relationship. The findings indicate community stigma is connected to increased parental burnout and poorer parent child relationship. Reducing community stigma as well as providing support for parents in managing their mental health can be beneficial for improving Family functioning and parent child interactions in families of children with ASD.

I. INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction as well as restricted or repetitive patterns of behavior, interests, or activities

(American Psychiatric Association, 2022). These symptoms are demonstrated from early childhood through adulthood, regardless of language ability, cognitive level, adaptive functioning, or severity of behaviors (Lord et al. 2020). The effects of a diagnosis also extend to the child. It impacts how family's function. Parents must manage demands including communication difficulties, challenging behaviors, sensory aversions, therapy regimens, school requirements, financial burdens, and ambiguity for your child's future independence (Bonis, 2016; Schopler & Mesibov, 1984). In Pakistan, the mother is usually responsible for day-to-day care, therapy visits, school problems, behavioral problems, and household chores. These responsibilities often generate additional stress like supporting extended family members and maintaining the family's honor. These responsibilities, coupled with lack of formal supports and social judgment can contribute to a risk for psychological burnout (Imran et al. 2011; Minhas et al., 2015). So, a better understanding of the psychosocial experiences of the mother is an important area of research and family centered services. These types of responses are stigma defined as labelling stereotyping separations, status loss and discrimination occurring within unequal social relationships (Link & Phelan, 2001). For parents of children with autism, stigma is always connected to. Parents are devalued both for their child's diagnosis and for being responsible for the child's condition or behavior (Gray, 2002; Kinnear et al. 2016). Perceived community stigma: is characterized as how parents think the wider community holds negative attitudes (stigma), stereotypes, or discrimination toward autism as well as toward families with children with autism (Zuckerman et al. 2018).

This is not the same as affiliate stigma, which relates to feelings of shame and self-blame (Mak & Kwok, 2010). Even if the mother does not perceive the labels as relevant to her, she may experience a strong social rejection. (Papadopoulos et al. 2019; Zuckerman et al. 2018). Community stigma is not merely a social problem. It represents a contextual risk factor for parental adjustment (Mikolajczak & Roskam, 2018). Parental burnout is a distinct occurrence specific to parenting, that differs from general parenting stress, depression, or general burden of care (Roskam et al. 2017 2018) A Based on the Balance Between Risks and Resources (BR 2) theory, burnout develops when the preschooler demands of parenthood lay continually beyond individual, familial and environmental abilities (Mikolajczak & Roskam, 2018). The syndrome is characterized by parental role exhaustion, emotional detachment from the children and with one's other self as a parent, and a reported sense of being fed up with parenthood (Roskam et al. 2018. Specific exhaustion has been related to decreased warmth, more withdrawal, and in more extreme cases, neglect or harsh responses (Mikolajczak et al. 2018 2019). Burnout is a more severe disequilibrium characterized by a depletion of the parent's emotional resources over time (Mikolajczak & Roskam, 2018). Signs of burnout include emotional unavailability to the child, a decrease of patience and satisfaction with parenting and problems with staying positively engaged with the child (Hubert & Aujoulat, 2018; Roskam et al. 2018).

These symptoms adversely affect family functioning and child psychological safety. The nature of the parent child relationship has been identified as a key thing in the adjustment of children. Healthy parent child relationships are warm close trusting, communicative and nurturing (Pianta 1992 1994). Such relationships promote children's sense of security, enable learned social skills and foster effective behavior regulation. Poor quality parent-child relationships are characterized by conflict hostility unpredictability and emotional detachment. Experienced attachment theory suggests an infant depends upon a caregiver being emotionally accessible to provide safety and to enable the regulation of emotions (Bowlby, 1969). In cases of parental exhaustion or social social isolation, parents may have less capacity for this function. The quality of a parent's relationship with their children is often affected by the mental health and well-being of the parent. Parents with depression, chronic stress, or burnout have been found to struggle to be warm, patient, and responsive reliably (Belsky, 1984; Mikolajczak et al. 2019). The authors propose that community stigma has an impact on family adjustment over and above the level of symptoms exhibited by the children. Studies from collectivist cultures demonstrate that this risk may be intensified since family status is highly correlated with social standing (Mak & Kwok, 2010; Minhas et al. 2015). Despite an increase in awareness of the autism spectrum disorder in Pakistan, there were many misconceptions about ASD. Autism is still sometimes accused of being caused by poor parenting, supernatural factors, and family problems (Imran et al. 2011; Minhas et al. 2015).

Pakistani parents have been reported as having experienced criticism from family members, neighbors, and the community. These reports highlight the importance of investigating the local context of perceived stigma, rather than presuming Western findings can be generalized. Cross-national research further indicates that those parents

with developmentally disabled children had a greater chance of burnout than did parents with typically developing children (Mikolajczak et al. 2019; Roskam et al. 2018). Exhaustion can occur gradually as the care becomes more prolonged over a number of years. Parents may become increasingly tired or guilty about their feelings towards parenting (Hubert & Aujoulat, 2018). In populations of children with ASD, it seems the risk of burnout is mainly high due to the need for ongoing therapy, managing behavior, fighting for appropriate education, financial burden and the uncertainty of future independence of children throughout childhood and adolescence (Karst & Van Hecke, 2012). Autism studies in Pakistan have been more concerned with diagnosis, professional knowledge, caregiver burden, and community access to services (Imran et al. 2011; Minhas et al. 2015). Issues related to community stigma, burnout, and family relationships are still being debated. These questions can be answered through this study, Our research focused on investigating the relationships among perceived community stigma, parental burnout, and the parent-child relationship of the mothers of children with autism spectrum disorder ASD living in Lahore who are being served by the private sector autism centers.

We further wanted to see if perceived community stigma and parental burnout are the significant predictors of the parent-child relationship, "The research was mainly underpinned by the BR theory (Mikolajczak & Roskam, 2018). Apart from that, it relied upon Belsky's (1984) process model, Bowlby's (1969) attachment theory, Bronfenbrenner's (1979) ecological model and finally Bandura's (1986) social cognitive theories. In this context, stigma is defined as the contextual risk. The exhaustion of parental energy or parental burnout is the outcome reflecting the decrease of resources or reserves. Meanwhile, the parent-child interaction people see as the family outcome most directly affected if these resources are exhausted. We investigated four hypotheses, our first hypothesis implied that perceived community stigma is closely related to higher levels of parental burnout. Our second hypothesis indicated that community stigma is inversely related to the parent-child relationship. Our third hypothesis stated that the parental burnt out can negatively affect the parent-child relationship as well. Lastly, the fourth hypothesis implied that the joint effect of both community stigma and parental burnout may have a large role in determining the quality of the parent-child relationship.

Hypotheses

1. There can be a significant correlation between perceived community stigma and parental burnout among parents of children with autism spectrum disorder.
2. There can be a significant correlation between perceived community stigma and parent child relationship among parents of children with autism spectrum disorder.
3. There can be a significant correlation between parental burnout and parent child relationship among parents of children with autism spectrum disorder.
4. Perceived community stigma and parental burnout can be significantly predict parent child relationship among parents of children with autism spectrum disorder.

II. METHOD

Participants

The sample for the present examines consisted of 300 mothers selected through convenience sampling from diverse private autism centers and special educations in Lahore. The mothers' children had to be between 4 and 12 years of age and actively receiving continuous services from private autism centers for a minimum of 6 consecutive months. Participants who met the inclusion criteria and gave knowledgeable consent have been recruited. Inclusion criteria were: a mother of a child diagnosed with an autism spectrum disorder (ASD), receipt of services through a private autism center for the child, age of 18 years or over. Participants were excluded if they had any severe psychiatric disorder that may affect their capacity to complete the questionnaires, any cognitive impairment. A demographic form was used to gather demographic data that included age education marital status, type of family, previous psychological counseling history, psychiatric history, and chosen child's data among this: These variables described the sample and were used to assess eligibility.

Measures

Following instruments were used to measure the variables including: [I] Demographic Sheet: On the basis of literature, the demographic variables of age education marital status, type of family, previous psychological counseling history, psychiatric history were explored. [II] The Parent Perceptions of Community ASD Stigma Scale (PPCASS): The perceived community stigma was assessed with 11-item scale created by Zuckerman et al. (2018). The items measured parents' perceptions of community endorsement of stigma toward ASD and children with ASD and their families. Adolescents responded to the scale using a Likert type scale. The higher the score on this scale, the higher the perceived community stigma. Previous studies have established that the scale measures community external judgments rather than internal self-blame (Zuckerman et al. 2018). Cronbach's alpha was computed to evaluate the internal consistency of the scale in this sample, resulting in .789 which is acceptable for a reliable scale. [III] Parental Burnout Assessment (PBA): Parental burnout was assessed with the 23-item PBA (Roskam et al. 2018). The four subscales assess exhaustion with the parenting role, contrast with a previous parenting self, feeling fed up, and emotional distancing. Each item was rated on a 7-point scale (0=never to 6=every day). Higher scores on the PBA are indicative of higher levels of parental burnout. Roskam et al. (2018) selected the PBA because it captures burnout scales specific to parenting instead of job burnout or general emotional distress scales (Roskam et al., 2017). In this study Cronbach's alpha=.796. [IV] Child Parent Relationship Scale (CPRS): This scale was assessed with the 15-item short form of the child parent relationship scale (CPRS; Pianta, 1992). This scale measures general relationship quality, to be exact the extent to which the parent and child are attached and the level of conflict between them. Higher scores would indicate more positive relationships. The CPRS is widely used in child development and family research (Pianta 1992). In this sample Cronbach's alpha was.785, indicating acceptable reliability.

Procedure

After obtaining ethical approval from the Department of Psychology and the ethics review board, permission was granted to select private autism centers, therapy clinics and special education institutions. Prospective participants were contacted via these establishments and were screened according to inclusion and exclusion criteria. Participants have been confident of the confidentiality in their responses and knowledgeable that their participation became voluntary, with the right to withdraw at any time. The self-record questionnaires, including the demographic form, have been administered in English. The management method took about 20–25 minutes. The researcher became present for the duration of the fact series to offer clarification if wanted and to make certain standardized administrations. After completion, all responses have been carefully reviewed, and incomplete or inconsistent questionnaires have been excluded from the very last analysis. The accrued facts were then coded and entered into SPSS for statistical analysis.

III. RESULTS

Table I: Psychometric Properties of Study Variables

Variables	M	SD	Range	α
Parent–child relationship	51.52	8.49	24–71	.78
Parental burnout	41.42	17.49	4–104	.79
Community stigma	16.72	4.64	11–35	.78

M = Mean; SD = Standard Deviation; α = Cronbach's alpha coefficient.

The results indicated that all three measures demonstrated satisfactory internal consistency reliability. Specifically, the Parent–Child Relationship Scale showed acceptable reliability (α = .78), the Parental Burnout Assessment demonstrated acceptable internal consistency (α = .79), and the Community Stigma Scale also exhibited acceptable reliability (α = .78). These Cronbach's alpha coefficients suggest that the instruments used in the present study were sufficiently reliable for assessing the respective psychological constructs. Regarding descriptive statistics, the mean score for parent–child relationship was 51.52 (SD = 8.49), indicating a moderate to relatively high level of positive parent–child relationship among the participants. The mean score for parental burnout was 41.42 (SD = 17.49), reflecting moderate levels of burnout with considerable variability across participants.

Similarly, the mean score for community stigma was 16.72 (*SD* = 4.64), suggesting that parents experienced varying levels of perceived community stigma.

Table II: Pearson Correlations among Parent Child Relationship, Parental Burnout, and Community Stigma

Variables	<i>M</i>	<i>SD</i>	1	2	3
1. Parent child relationship	51.52	8.49	---	-.336 **	-.236 **
2. Parental burnout	41.42	17.49		---	.218 **
3. Community stigma	16.72	4.64			---

***p* < .001

The results indicated statistically significant relationships among all three study variables at the *p* < .001 level. Specifically, the parent–child relationship demonstrated a significant negative correlation with parental burnout, *r* (298) = −.336, *p* < .001, indicating that higher levels of parental burnout were associated with poorer parent–child relationships. Likewise, the parent–child relationship showed a significant negative correlation with community stigma, *r*(298) = −.236, *p* < .001, suggesting that parents who perceived greater community stigma reported less positive relationships with their children.

Table III: Linear Regression Showing Parental Burnout and Community Stigma as Predictors of Parent Child Relationship

Predictors	B	95% CI for B		SE B	β	R ²
		LL	UL			
1. Constant	62.44	58.78	66.10	1.86	---	.141
2. Parental Burnout	-.145	-.198	-.092	.027	-.299	
3. Community stigma	-.312	-.511	-.113	.101	-.170	

Note. CI = confidence interval; LL = lower limit; UL = upper limit. The regression model was significant, *F* (2, 297) = 24.33, adjusted *R*² = .135.

The regression model was statistically significant, *F* (2, 297) = 24.33, *p* < .001, explaining 14.1% of the variance in parent–child relationship (*R*² = .141, Adjusted *R*² = .135). These findings indicate that parental burnout and community stigma jointly contributed significantly to predicting parent–child relationship. Specifically, parental burnout emerged as a significant negative predictor of parent–child relationship (*B* = −.145, *SE* = .027, *β* = −.299, 95% CI [−.198, −.092]), indicating that higher levels of parental burnout were associated with poorer parent–child relationships. Similarly, community stigma was also found to be a significant negative predictor of parent–child relationship (*B* = −.312, *SE* = .101, *β* = −.170, 95% CI [−.511, −.113]), suggesting that greater perceived community stigma was associated with lower levels of positive parent–child relationship.

IV. DISCUSSION

The present study examined the community stigma faced by Pakistani mothers of children with autism spectrum disorder (ASD), parental burnout experienced by them and their perception for their mother child relationship. These parents received services from privately funded autism centers. Parental burnout was more influential on quality of parent child relationship than stigma. The results from the psychometric analysis also revealed that all three tools used in the study utilized. The alpha scores are acceptable for research and consistent with previous findings for these measures (Pianta, 1992; Roskam et al. 2018; Zuckerman et al. 2018). The data also showed that the distribution of scores was appropriate for parametric analysis. The reported average levels of community stigma and burnout for mothers were moderate, and the majority reported overall positive relationships with their children, which is an important combination, showing most mothers were still close with their children despite reports of community stigma and burnout, but that the differences in their reported stigma and burnout were tied

to differences in the quality of their relationship. The initial hypothesis predicted to have a positive relationship between perceived community stigma and paternal burnout. This is a weak moderate effect, but is statistically significant and makes sense in theory. Mothers who perceived negative attitudes misconceptions criticism and judgement about autism in the community scored higher on burnout (Mikolajczak & Roskam, 2018).

Community stigma may influence parenting in different ways. First, stigma introduces an additional emotional burden to the difficult parenthood struggle. Mothers have to fulfill the needs of the child and simultaneously worry about how individuals like family, neighbors, or others will behave. Second, community stigma contributes to the reduction of available social support. Mothers who perceive themselves as rejected or misunderstood may withdraw from social interactions, be reluctant to seek help, or hide the diagnosis of the child (Gray, 2002; Zuckerman et al., 2018). This withdrawal would eliminate an available source of support. Third, community stigma may diminish a mother's sense of efficacy. Repeated social evaluation can result in a parent losing confidence and increasing their self-doubt. Continually losing confidence may eventually sap a parent's emotional strength. These are consistent with similar studies from different parts of the world which have established the evidence of the association between stigma and poor mental health among caregivers (Kinnear et al. 2016; Mak & Kwok, 2010). Replicates previous findings that perceived community stigma appears to predict the experience of parental burnout, rather than general stress or stigma from others. And this has a special significance with Pakistani mothers. The cultural explanation helps to contextualize why community stigma predicted burnout to a limited degree. Pakistani mothers who are stigmatized and accused by community members of not just having a disabled child but of poor parenting behavior experience additional communities' specific stressors that can aggravate care giving burden. Interestingly that correlation is not very high. Child severity of behavior, financial burdens, spousal support, sleep deprivation, and availability of services all could affect burnout (Karst & Van Hecke, 2012; Mikolajczak & Roskam, 2018).

Community stigma is definitely one of many concerns. Yet, it is significant because community stigma is socially generated and can be altered through societal efforts and education. The second hypothesis proposed an inverse association between perceived community stigma and the parent-child relationship. Mothers who experienced more community-based stigma had fewer positive relationships with their children. There are many factors involved. Community stigma might augment parental worry and diminish confidence leading to more difficult being warm and understanding (Gray, 2002; Pianta, 1992). Constant criticism might lead parents to be preoccupied with being judged by others and less present when attending to daily needs (Kinnear et al. 2016). And, the stress of exclusion might take away the informal support that normally aids parents after difficult days and leaves them approaching their children with greater emotional unavailability. The more burned out a mother was, the fewer positive daily interactions she had with her children. This highlights the significance of a parent's mental state on everyday family functioning. Persistent tiredness could impair mothers' ability to reliably respond to their children's social and emotional needs. Fatigue can adversely affect a mother's patience, empathy, and emotional space leading to greater difficulty establishing positive ways of speaking with and for their children (Mikolajczak et al. 2019; Roskam et al. 2018).

Previous international studies show that parental burnout is tied to lowered levels of emotional involvement, lowered satisfaction with motherhood and increased psychological detachment (Hubert & Aujoulat, 2018; Mikolajczak et al. 2018 2019; Roskam et al, 2018). The fourth hypothesis hypothesized that observed community stigma and parental burnout shapes parent child relationship a lot. Linear regression further supported this hypothesis. The regression model was significant and explained variance in parent child relationships. Both variables contributed uniquely to the model, although parental burnout exerted a slightly greater influence than perceived community stigma. So environmental and psychological factors are important, but parental burnout seems to be more directly related to daily interactions with the parent child. When controlling for community, emotional exhaustion still resulted in greater short-term deficits in warmth, patience and responsiveness. The findings of the regressions provide evidence for the BR2 theory, revealing that parental burnout mediates the association between parenting risks and family functioning (Mikolajczak & Roskam, 2018). When a mother perceives stigma of the community, her stress level may be heightened due to increased instances of blame, exclusion, and lack of support. These factors may threaten her psychological resources, resulting in increased burnout and subsequent decreases in parent child relationship quality. Though mediation was not formally tested

in this study, the empirical pattern observed was consistent with theory suggesting parenting risks influence parenting outcomes via negative consequences for psychological wellbeing. Levels of parental stigma increase any burden experienced, and are linked to compromised quality of the parent child relationship.

There are many strengths to this study. It is one of the few quantitative studies in Pakistan to investigate perceived community stigma, parental burnout, and the parent child relationship in one study. Standardized instruments with a sufficient level of internal consistency were utilized. A sample of 300 mothers had sufficient statistical power to facilitate correlation and two predictor regression. Finally, BR2 theory provided a comprehensive and rational explanation of the interpretation of the findings (Mikolajczak & Roskam, 2018). A few limitations should be pointed out. The study was correlational in design, which limits interpretations about causality. It may be that a poor parent child relationship causes burnout, not the other way around. Alternatively, being more tired might make one have more negative attitudes toward community. For these reasons, a study with a longitudinal design would be desired to test these relationships. Second, all measures were self-report, and because of this, could have been influenced by socially desirable responding, transient emotional states, or common method bias. Third, participants were conveniently recruited from private autism specialty centers in this city; this way, the results may not be generalizable to fathers, to public-sector families, to families without access to autism specialty centers, or to those in rural locations. Fourth, other potential covariates including number or severity of child's behavior problems, family income, or social support were not included in the current study. These factors could account for additional variance and may influence the relationships studied.

Future studies should utilize a longitudinal design to determine whether community stigma perception predicts higher levels of parental burnout over time and whether changes in burnout then predict later changes in parent child interaction. Further studies are needed on social support, coping strategies resilience parenting self-efficacy, marital satisfaction and psychological flexibility as mediators or moderators (Bandura, 1986; Mikolajczak & Roskam, 2018). Future studies may incorporate child related variables, to be exact ASD severity and behavior problems, to allow a more comprehensive test of Belsky's (1984) process model. Comparisons between public and private service settings might uncover differences in levels of stigma and support. Including Child related factors like ASD severity as well as behavior problems, which is a strength of our study, should be considered in future efforts to replicate the findings of Belsky's (1984) process model. Further investigation should include data collection from additional parental figures, i.e. father's grandparents and other caretakers. It may be helpful to compare public versus private service environments to determine whether there are differences in levels of community perception of stigma and esteem, as well as available support or number of supports. Using qualitative or mixed methods approaches can give in depth information on how the community perception of stigma is individualized and how parents perceived the protective aspect of safeguarding her and her child's reputation.

V. CONCLUSION

The main objective of this research was to assess how mother's perceptions of community stigma correlate with their burnout and the way mothers interact with their child with children diagnosed with autism spectrum disorder. The study outcomes revealed that the mothers' perception of community stigma is tied to parent's burnout at a higher level; that is, mothers who perceived negative societal judgment are more likely to feel their emotional exhaustion (Glbetekin et al (Glbetekin et al., 2024; Kinnear et al., 2016). 2024; Kinnear et al. 2016). Also, both parental burnout and feeling society judged them had a negative effect on the quality parent-child relationships, and the parent-child relationship was more strongly and negatively linked to parental burnout, indicating it's the most influential factor. Per the results of the regression analysis, parental burnout and mothers' perception of their stigma together are a good indicator of the parent-child relationship and explain variance in parent-child relationship, which is similar to the Balance between Risks and Resources (BR) model. This model explains that constant parenting difficulties and scarce resources lead to burnout (Mikolajczak & Roskam, 2018). Despite the hypotheses of the study were all fulfilled, the limited percentage of explained variance shows that other aspects, like parental stress, social support, coping strategies, child-related variables, and family resilience, among others, can also define the parent-child relationship, that's why the need to investigate them in the future studies.

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