

ORIGINAL ARTICLE

A CROSS-SECTIONAL STUDY OF EMOTIONAL EXHAUSTION AMONG PARENTS OF AUTISTIC CHILDREN IN PAKISTAN

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ABSTRACT

Background: Emotional exhaustion is globally renowned terminology and described as feeling of being emotionally overstretched, or drained of one's emotional and physical resources. Parenting an autistic child has severe consequences for not only the autistic child but the parents as well. Most of the parents go through stress, phases of skepticism, suspicions, highly grief and despair, self-accusation and guiltiness, while remaining go through the feeling of inability to help and persistent shock. **Objective:** This study was designed to find out the level of Emotional Exhaustion in the parents of autistic children. **Methodology:** The study used an exploratory cross-sectional study design. The sample size was 60 out of which 30 were mother and 30 were fathers. The sample consisted of parents (both Gender), with at least one autistic child, parents' Age range of was 18 years to 50 years, Divorced and Widowed family was excluded, Family with husband having more than one wife were excluded, Age of the autistic Child/Children range between 4 year- 26 years. Parental Burnout Assessment sub-scale (Emotional Exhaustion) was partially used as a survey questionnaire for data collection.

Results: There was substantial variance found in the mean of emotional exhaustion in fathers was 13.73 ± 9.80 and mean score in mothers was 18.46 ± 13.61 . 68% parents were less emotionally exhausted, 15% were moderately exhausted and 21% were high at emotional exhaustion. **Conclusion:** The current study conclusively showed that mothers were more emotionally exhausted than fathers.

Key Words: Emotional Exhaustion, Burnout, Autism- spectrum disorder, Autism, Parents

INTRODUCTION

Emotional exhaustion in simple words is "The result of intense physical, affective, and cognitive strain, such as a long-term result of prolonged exposure to certain job demands." ¹ Maslach viewed "emotional exhaustion" as "The decline of energy from the subconscious or the depletion of emotional capabilities." ² Emotional exhaustion commonly coexists with physical exhaustion, and its symptoms include a lack of energy, less sleeping, family troubles, and an increase in drinking.³ The presence of social or professional support networks has been linked to the level of physical exhaustion in parents of disabled children, and the parents that have strongly bonded social networks, prove to adjust to their children's needs in a more better way, and their functioning with their family is also adorable coupled with a high levels of well-being. ⁴

Numerous studies have identified several factors responsible or effecting emotional exhaustion. A well-known example is that of the conservation of resources (COR) model of stress. ⁵ This model narrates that the emotional exhaustion is more probable to happen when concrete resources vanish, or when there exists a perceived fear of loss of the resources, or even when resources are inadequate to fulfill demands or fall below expected return.

Parenting an autistic child becomes a major source of exhaustion for some parents resulting in burnout. Therefore, two things move and co-exist simultaneously; one self-fulfillment of love for the child, and the other exhaustion in fulfilling parenting role of autistic child.

A study in 2018 showed emotion exhaustion as 0.85 with p-value <0.001 displaying the most prominently significant dimension in mothers. ⁶

International Consortium of IIPB (International Investigation of Parental Burnout) have published results of their researches conducted worldwide across 42 countries in 2018-2019, the salient of which are; The prevalence of parental burnout (PPB) greatly varies across regions.⁷ According to Isabelle Roskam, Pakistan has 0.9% prevalence of burnout of parents. Another research study assessed occurrence of emotional exhaustion in 103 parental couples who were parents of children with Down Syndrome (DS); it also discovered the rate of emotionally drained and depressed mothers, in contrast with fathers. The study suggested a 52.64% occurrence of emotional exhaustion, more in mothers as compared to fathers⁸.

Another study conducted in 2010 by Lindstrom and colleagues shows that 44.4% of mother and 28.4% of father suffered Parental burnout, while parenting children who are suffering from prolonged diseases like type 1 diabetes mellitus (T1DM) and irritable bowel syndrome (IBS) with mean 3.59 ± 1.54 of emotional exhaustion in T1DM, and 3.57 ± 1.20 in IBS.⁹

A study examined how social support influences the connection between emotion regulation, psychological distress, and well-being among caregivers of children with intellectual disabilities. The study involved 315 caregivers aged between 18 and 62 (average age = 36.99, SD = 9.90; 38.7% male, 61.3% female), who completed various scales, including the Emotion Regulation Questionnaire, Multidimensional Scale of Perceived Social Support, Depression Anxiety Stress Scale, and Psychological Well-being Scale. The findings showed that social support played a significant role in moderating the relationship between cognitive reappraisal, expressive

suppression, and psychological well-being. However, social support did not have a significant moderating effect on the relationship between these emotion regulation strategies and psychological distress. The results suggest that caregivers with strong social support are more likely to experience better psychological well-being when using cognitive reappraisal and expressive suppression.¹⁰

In mothers of children with intellectual disabilities (ID), anxiety and depression were strongly linked to them often using negative thinking patterns, like imagining the worst (catastrophizing), and rarely using more positive strategies, such as focusing on positive aspects, rethinking the situation in a helpful way, or putting things into perspective. Additionally, depression, but not anxiety, was connected to a tendency to dwell on problems (rumination) and avoid focusing on making plans to solve issues.¹¹

Consistently, Hu et al. (2019) found that ER difficulties in parents of children with ASD were associated with heightened parental psychological distress.¹² Enav et al. (2019) suggested that a key way for parents of children with autism spectrum disorder (ASD) to cope with high levels of stress is through emotion regulation (ER). Emotion regulation, in turn, depends on a skill called mentalization or reflective functioning, which is the ability to understand both your own thoughts and feelings, as well as those of others.^{13, 14}

Carreras et al. (2019) proposed that parents' ability to manage their emotions (emotion regulation) might play a key role in how their stress affects their parenting. In other words, it's not just the stress itself that affects how they parent, but how

well they can control their emotions while dealing with that stress.¹⁵

Conclusively, the phenomenon has only been studied/ tested in very few cultural settings, and not in abundance across wide range of cultures, in various geographical regions of Pakistan as well as of the world. Therefore, the study is essential to address this existing gap and conduct plentiful studies across dissimilar cultures, in order to add to the existing knowledge.

It is also vital to establish and improve required psychological need services, based on empirical evidences. As this study focuses not only on the likely negative outcomes of having an autistic child, but likewise to examine likely positive

outcomes. Further, its predictors can be used to innovate new effective psychological clinical interventions that can be effectively used with parents of ASD children.

Previous researches conducted, heavily rely upon maternal reports, whereas, this study includes both father and mother (family atmosphere), thus presenting more holistic results of the phenomenon which has never been explored in Pakistan. The purpose of this study is therefore, to provide evidence-based voice to the exhausted parents of Pakistani autistic children, by empirically exploring emotional exhaustion harvested in raising them.

MATERIAL AND METHODS

Study Design: It was an explanatory research based on cross-sectional survey design.

Study Setting: The population of this research study, encompassed parents of autistic child/children living in Lahore city.

Sample Size: The sample size was 37. Adding 20% drop out, the sample size was 44.4. So, the estimated sample size was 50. However, the researcher had taken 70 samples, after scrutiny total of 60 parents were analyzed. Out of which 30 were mother and 30 participants were fathers.

Sampling Technique

Non-probability purposive sampling technique was adopted due to being an unknown percentage of autistic population in Pakistan as well as provinces, divisions, districts and cities.

Participants:

Inclusion / Exclusion Criteria:

- Parents of both gender¹⁶
- At-least 1 autistic child.¹⁶

- Age range of parents was 23 years to 50 years¹⁶
- Divorced and Widowed family was excluded¹⁶
- Family with husband having more than one wife were excluded
- Age of the Child/Children range between 4 year- 26 years¹⁶

Data Collection Tool

IIPB protocol label and syntax wave 2, version April 16th 2020 HVBRH was partially used (Sub-scale; Emotional Exhaustion). Item Number 1, 3,4,8,9,10,15,21 & 23 of Parental Burnout was used for computing Emotional Exhaustion. COMPUTE PBA Exhaustion = SUM (item 1, 3,4,8,9,10,15,21, 23). Reliability has already been pilot tested and being used in almost 60 countries across the world. Cronbach's alphas were 0.92, 0.89, 0.85 for the three subscales and 0.91 for the global score (i.e., the sum score of all PBI items).

0.94 and 0.92 for Emotional Exhaustion.

Data Collection Procedure: The sample was collected from various Autism Rehabilitation Centers, however, as some parents did not accompany their children due to commitments of

RESULTS

The results showed that out of n=60, there were 30 Mothers and 30 Fathers. The statistics shows that the mean score of age was 34.11±5.91 with minimum age was 21 years and maximum age was 49 years. The statistics showed that 10 (16.7%) of the parents had attended high school. 22 (36.7%) of the parents had attended university till graduation. 23 (38.3%) had gone till 16 years of education (Masters) and 5 (8.3%) had done 18 years of education (MPhil.). The mean score of educational level was 3.38±.86. The statistical results showed that 17(28.3%) were unemployed mothers and fathers, mainly mothers. 10 (16.7%) were self-employed doing their own business. 33 (55%) were employed in govt. or private companies. The mean score of employment status was 2.26±0.88. 39 (65%) of parents were living as a nuclear family (basic family unit). 21 (35%)

various nature, therefore the parents were contacted (contacts provided by rehab centers with permission) and data was collected through means of their convenience (on online form), with the signed informed consent from the parents.

parent living in a joint family system (extended family). The mean score was 1.35±0.48. 46 (76.7%) of parents had only autistic child. 9 (15%) had 2 autistic children. 3 (5%) had 3 autistic children while 2 (3.3%) had 4 autistic children.

The results estimated that the minimum emotional exhaustion was 0 and 51 was maximum score of emotional exhaustion. Mean score was 16.10±12.09 (as shown in table I). The outcome of this study predicted that 63% were low emotionally exhausted, 15% were moderately emotional exhausted. 21.7% were high at emotional exhaustion. (as shown in table II) Emotional exhaustion was low in 22 fathers and 16 mothers, moderate in 4 fathers and 5 mothers whereas, high in 4 fathers and 9 mothers of autistic children. (as shown in table III).

Table-I: Descriptive statistics of Emotional exhaustion

	Mean	S.D	Minimum	Maximum
<i>Emotional Exhaustion</i>	16.10	12.09	0.00	51.0

Table-II: Level of emotional exhaustion

Level of Emotional Exhaustion	Frequency	Percent (%)
<i>Low</i>	38	63.3
<i>Moderate</i>	9	15.0
<i>High</i>	13	21.7
<i>Total</i>	60	100.0

Table-III: Level of emotional exhaustion among parents

		Level Of Exhaustion			Total	χ ² (p-value)
		Low	Moderate	High		
<i>Gender</i>	<i>Fathers</i>	22(73.3%)	4(13.3%)	4(13.3%)	30(100%)	2.98 (0.225)
	<i>Mothers</i>	16(53.3%)	5(16.7%)	9(30%)	30(100%)	
<i>Total</i>		38(63.3%)	9(15%)	13(21.7%)	60(100%)	

DISCUSSION

The present study results revealed that there was a substantial variance found in the mean of

emotional exhaustion in fathers was 13.73±9.80 and mean score in mothers was 18.46±13.61.

In 2016 Jaramillo and colleagues found that 38 of the 44 households with trisomy 21 children where just one parent experienced emotional exhaustion belonged to the mother, whereas the other six belonged to the father. In 10 marriages, both parents had the illness. 103 families out of a total of 54 met the requirements for emotional exhaustion, presenting a prevalence of 52.64%.⁸ Compared to her husband, mothers are 3.6 times more likely to experience emotional exhaustion (IC 95% 1.3–9.7).

Results also showed positive significant correlations of parenting stress with emotion dysregulation and inter-parental conflict .46, with negative correlations for SDC -.47. Emotion dysregulation presented a negative correlation with SDCO -.36 and a positive one with inter-parental conflict .33.¹⁷

A study results of the descriptive analysis showed that the mean (standard deviation) of the scores of mothers of children with specific learning disorders in the reappraisal sub-scale of emotion regulation was 22.67 (8.01) and in the suppression sub-scale of emotion regulation was 15.19.¹⁸

In 2020, Ahmed et al. investigated how mothers use different cognitive emotion regulation (ER) strategies. They found that the average use of certain strategies varied significantly. Specifically, they found significant effects for the strategies of Acceptance, Positive Refocusing, Refocus on Planning, and Positive Reappraisal, meaning these strategies were used differently by mothers. The

statistical tests (one-way ANOVAs) showed that the differences were significant (p-values less than 0.05). For example, Positive Refocusing had a p-value of 0.004, indicating it was used in a meaningful way. However, for other strategies, no significant differences were found (p-values were greater than 0.17), meaning those strategies were used similarly across the participants.¹⁹

In 2023, research found a significant link between parenting styles, emotional regulation, and how well parents adjust socially. The study also showed that emotional regulation plays a key role in how parenting styles affect parents' social adjustment. This relationship was measured at 0.438, which is a positive and statistically significant value at a 95% confidence level. Additionally, the study found that the effect of emotional regulation on parents' social adjustment was strong, with a coefficient value of 0.654, indicating a positive and meaningful impact.²⁰

According to few studies, mothers experience emotional exhaustion more frequently than fathers do.²¹ Another study concluded that using an independent samples t-test, it was determined whether or not parental burnout levels varied based on the parent's gender. The study shows no significant difference in the amount of parental burnout based on the parent's gender. However, the PBS results showed that dads' burnout levels (x 95.90) were lower than mothers' burnout levels (x 101.67).²²

CONCLUSION

The percentage of emotional exhaustion in parents of autistic children estimated moderate to high in the study. The current study concluded that mothers showed more emotionally exhausted than fathers.

LIMITATIONS: The major difficulties/ hurdles in accessing parents of autistic children as well as in data collection were; some parents were shy, some had complex of being less/ uneducated, some were unavailable due to their prolonged professional /other engagements, and Few hesitated / avoided sharing their opinions, as they perceived that having an autistic child is a social stigma. Most of the autistic child(ren) were accompanied by caregiver (either some relative or maid) who were not the appropriate respondents for the study.

Recommendations: To further evaluate the other variables the researchers' may include parent's engagement in terms of hours spend with their children. As cultural variance significantly influences the emotional exhaustion, it is recommended to analyze socio-demographic variables like; ethnicity, religion and how much one believes and is practicing in his/ her religion. Age of autistic children, autistic severity, and temperament of the autistic children, their special needs and behavior patterns are the most influential factors in emotional exhaustion. Parenting style and parent's personality influence on emotional exhaustion can also be assessed, as variance showed in in the level of emotional exhaustion of the parents. Another factor appears crucial to be explored, is the quality of the couple relationship as well as the threats/ hazards which the emotional exhaustion poses to the quality of the couple relationship.

Declaration of No Conflicting Interest: There was no conflict of interest among the authors.

Funding Details: It was an individual effort; no sponsorship nor grant was given financial support.

Author's Contributions

MYQ: Main idea, Data collection and analysis, Methodology, **AZ:** Supervision, Final revision,
UN: Methodology, Data Collection, analysis and Manuscript writing

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