

Burden of care and Suicidal Ideation among Mothers of Children with Autism Spectrum Disorder: Perceived Social Support as a Moderator

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Abstract

Objective: To examine the moderation effect of perceived social support between burden of care and suicidal ideation among mothers of children suffering from Autism Spectrum Disorder.

Method: The descriptive cross-sectional study was conducted from September 2017 to February 2018 in the Pakistani cities of Islamabad Lahore, Gujrat, Gujranwala, Jhelum and Sialkot, and comprised of mothers of Autism Spectrum Disorder children aged 7-12 years who were selected conveniently from the special schools in their respective cities. Standardized tools were used to assess the burden of care, perceived social support and suicidal ideation among the participants. SPSS 21 was used for data analysis.

Results: Of the 373 mothers approached, 356(95.4%) responded, but the study was completed by 339(95.2%) of them. There was positive relationship ($p < 0.01$) between burden of care and suicidal ideation, and whereas results showed negative relationship among perceived social support, burden of care ($p < 0.001$) and suicidal ideation ($p < 0.001$). The burden of care positively ($p < 0.001$) and perceived social support negatively ($p < 0.002$) affected suicidal ideation. Perceived social support moderated the burden of care-suicidal ideation relationship ($p < 0.001$) among the mothers.

Conclusion: Social support provided by the significant others lowered the burden of care and suicidal ideation among mothers of children with Autism Spectrum Disorder.

Keywords: Burden of care, Suicidal ideation, Perceived social support, Autism Spectrum Disorder.
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Introduction

Burden of care is defined as the psychological, emotional, social and economic challenges that are experienced by a caregiver of mentally or physically ill person. Mothers being the caregiver of a child with Autism Spectrum Disorder (ASD) may feel burden of care because raising a child with ASD is a challenging task. ASD involves impaired communication, poor reciprocal social interaction and stereotyped repetitive behaviours. The routine lives of their parents, especially the mothers, become different compared to mothers with the typically developed children.^{1,2} This routine brings anxiety, stress and distress in the caregivers. The burden of care may get increased due to lack of social support in terms of social and financial responsibilities of the child.¹ Burden of care leads to psychological distress, poor quality of life, low energy level, fatigue as well as impaired emotional and physical

wellbeing of the caregivers.^{1,2} Literature reveals that almost 75% caregivers of ASD children are mothers compared to fathers and other family members. Therefore, they are more likely to experience negative effects of the burden of care and mild to moderate levels of psychological distress.³ This psychological distress due to burden of care may lead them towards suicidal ideation.⁴

Suicidal ideation refers to the thinking, reflecting and planning for suicide. The issue of suicide is becoming so common and serious that the experts have suggested to define suicidal behaviour as a disorder with a separate diagnosis in Diagnostic and Statistical Manual of Mental Disorders-V (DSM-5).⁵ Perceived burden and lack of social support among mothers of challenging children can be major factors of depression and stress among them which may further lead to suicidal ideation.^{1,2,4} Literature shows that raising children with disabilities is a very challenging task for the caregivers due to the children's limited cognitive and physical capabilities. The process of raising

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them demand awareness of dealing with the unique needs of disability, extra time, attention and expenses. Usually a single parent or caregiver without any social support cannot fulfil the needs of these children, and, consequently, the caregiver may suffer from depression and other psycho-social problems.⁶ Chances of poor mental health may also increase if the symptoms of disability are severe among ASD children.⁷ It is reported that mothers of ASD children have poor health compared to the mothers of the children with other developmental disorder such as Intellectual Disability (ID). Therefore, they are found to be more in need of special assistance in terms of health-related home services and social support.⁷ Challenges to raise an ASD child can be effectively dealt with through proper social support of the mothers, because it provides significant assistance by the family members and others to cope with stressful events and leads to successful adaptation of mothers of children with developmental disorders.⁸ Social support also appears to be a key in reducing the burden of caring tasks due to the engagement of mothers in pleasurable activities with family and friends which later contribute to diminishing probable chances of suicidal thoughts.⁹ Similarly, the inverse relationship between social support and burden of care among mothers of ASD children has been reported.¹⁰

ASD is a neurodevelopmental disorder.¹¹ It is characterised by deficit in two main areas; social interaction and communication, as well as limited and repeated pattern of behaviour, interest and activities. Along with its diagnostic features, the disorder may also cause intellectual, language and motor deficits. The overall prevalence rate of ASD is almost 1% while in the underdeveloped countries it ranges from 0.09% to 1.07%.¹² ASD is so serious and burdensome that it leads to serious psychiatric disorders among caregivers. Researchers report that the mother of ASD children seems more vulnerable to psychological problems compared to mothers of ID children and they are found to be hospitalised for a longer period of time for the treatment of psychiatric disorders.¹³ According to a study, they are so burdened that they are 40-200% more likely to die.¹⁴

Further, there is little or no focus on the health of mothers of ASD children and their suicidal ideation in literature. The current study planned to investigate the moderating effect of social support on the relation between burden of care and suicidal ideation of mothers with ASD children.

Subjects and Method

The descriptive cross-sectional study was conducted from September 2017 to February 2018 in the Pakistani cities of Islamabad Lahore, Gujrat, Gujranwala, Jhelum and Sialkot, and comprised of mothers of ASD children aged 7-12 years. The sample size was calculated by multiplying the number of items on the three data-collection tools by 10.¹⁴ The children were selected conveniently after getting informed parental consent and after permission was obtained from the heads of the schools. The children were reassessed by implying criteria given in DSM-5¹⁵ and those not meeting the criterion were excluded. Single mothers or those with more than 1 child with disability were excluded.

Urdu versions of the 19-item Burden Assessment Scale¹⁶ (BAS), 12-item Multi-Dimensional Scale of Perceived Social Support¹⁷ (MSPPS) and 5-item Suicidal Ideation Attributes Scale¹⁸ (SIDAS) were administered. Internal consistency (Cronbach alpha) of the three scales was $\alpha = 0.75$, $\alpha = 0.78$ and $\alpha = 0.81$. BAS measures the level at which the life of a caregiver has been affected by caring for a relative with a psychological disorder on a rating scale from 1 = 'not at all' to 4 = 'a lot'. Higher scores indicate more burden of care.¹⁶

MSPSS has been shown to have good internal consistency (0.88), test-retest reliability (0.85) and good validity. It has been translated into many languages and high score indicates more social support.¹⁷

Likewise, SIDAS is a reliable (Cronbach alpha = 0.91) and valid instrument. Convergent validity of SIDAS with the Patient Health Questionnaire 9 as well as with the Columbia-Suicide Severity Rating Scale frequency item had been $r = 0.65$ and $r = 0.61$ respectively.¹⁸ Responses are recorded on a 10-point scale and a higher total score indicates higher suicidal thoughts.

For the current study, SIDAS was forward translated into Urdu by a panel of five bilingual (English and Urdu) psychologists. The translations were scrutinised and a copy was generated keeping in view the conceptual meanings of the items. The final Urdu version was given to three other bilingual experts, who were unaware of the original SIDAS, for back-translation. The three back-translations were scrutinised and were compared with the original scale. The Urdu version was then finalised by making minor changes in the wording of one item. The Urdu version and original SIDAS were pilot-tested on a

group of 100 students in the final semester of Masters in Psychology course to establish cross-language validation by administering Pearson Moment Product Correlation which was $r = 0.84$.

Permissions were obtained from the authors of the tools to measure the variables as well as to translate SIDAS. For assessing the moderating role of perceived social support with burden of care and suicidal ideation, the Process Procedure version 3¹⁹ was run on SPSS 21.

Results

Initially, 409 children were selected, but 10(2.4%) were excluded for not meeting the DSM criterion. Of the 399(97.5%) families left, 26(6.5%) had to be dropped because there was either a single mother or there were more than one disabled children in the family. Of the 373(93.5%) mothers short-listed, 356(95.4%) responded, but the study was completed by 339(95.2%) of them. The highest number of cases belonged to Lahore 156(46%) (Table 1).

The relationship between burden of care and suicidal ideation was positive, but perceived social support had a negative association with burden and with suicidal ideation (Table 2).

The burden of care positively ($p < 0.001$) and perceived social support negatively ($p < 0.002$) affected suicidal ideation (Table 3). Perceived social support moderated the burden of care-suicidal ideation relationship ($p < 0.001$) among the mothers. In other words, participants who had perceived social support felt less burden of care and thus exhibited low level of suicidal ideation (Table 4).

Table-1: Description of cities, special schools and sample size (n).

Cities	Total No. of Special Schools	n (f)	Percentage
Lahore	8	156	46
Islamabad	4	58	17
Gujranwala	4	55	16
Gujrat	2	17	05
Jhelum	3	36	11
Sialkot	2	19	05
Total	23	339	100

Table-2: Spearman correlation of burden of care, suicidal ideation and perceived social support.

Sr#	Study Variables	r1	r2	r3
1	Burden of care	1	-0.53***	0.48**
2	Perceived Social Support	-	1	-0.61***
3	Suicidal Ideation	-	-	1

$r =$ correlation, ** $p < .01$, *** $p < 0.001$.

Table-3: Model Summary of the predictors of suicidal ideation on Process.

Variables	*b	LLCI	ULCI
Burden of Care	0.43***	0.332	0.458
Perceived Social Support	-0.35**	-0.388	-0.247
Burden of care* Perceived Social Support	-0.26**	-0.357	-0.170
R2	0.54***		
R2 change	0.04**		
F	88.49***		
Df	335		

*b=coefficients, ** $p < .01$, *** $p < 0.001$, LLCI: Lower levels for confidence interval, ULCI: Upper levels for confidence interval.

Table-4: Effect of Burden of care at values of Perceived Social Support.

Perceived Social Support	Effect (b)*	LLCI	ULCI
-0.72 (Low)	0.41**	0.36	0.47
-0.60 (Average)	0.36**	0.33	0.44
-0.45 (High)	0.22***	0.30	0.41

*b= coefficients, LLCI: Lower levels for confidence interval, ULCI: Upper levels for confidence interval

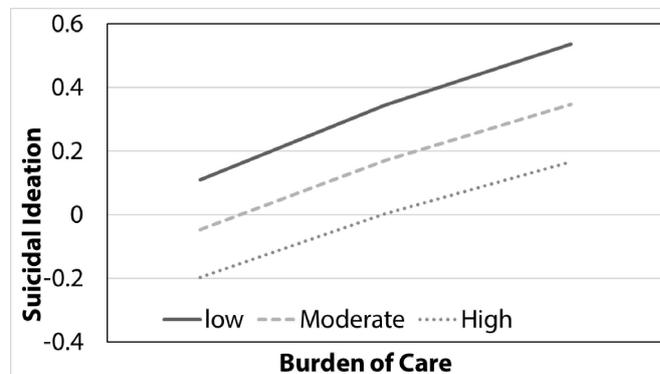


Figure: Effect of Perceived Social Support on Burden of Care and Suicidal Ideation.

Besides, high levels of perceived social support weakened the effect of burden of care on suicidal ideation among the participants (Figure).

Discussion

The current study planned to explore the relationship among burden of care, suicidal ideation and perceived social support, and to find the effect of perceived social support as a moderator on burden of care and suicidal ideation among mothers of ASD children.

Correlation results indicated a significant positive relationship between the burden of care and suicidal ideation of the mothers. It may be because the mothers of ASD children have to manage diverse roles of their lives in order to meet the challenges that the disability of their children pose on them.^{2,3,6,20} Therefore, they have been

found to experience higher levels of depression compared to their life partners and other family members. This depression may be a leading factor of suicidal ideation among such mothers.^{1,2,5}

Besides, a significantly inverse relationship of perceived social support was seen with burden of care and suicidal ideation. Results are in congruence with previous studies indicating negative relationship of perceived social support with both burden of care and suicidal ideation.²⁰⁻²² A therapeutic impact of social support on mothers can be justified by the fact that over half the mothers experience psychological distress significantly related with the low level of social support.²³ These statements are further supported by the moderation analysis.

Analysis revealed significant moderating effect of social support for burden of care and perceived social support. It was evident by the results that participants with higher level of perceived social support reported low level of burden of care and suicidal ideation. A reason of this moderating role of social support for suicidal ideation may be that ASD children have to visit healthcare centres frequently, use prescription drugs and need special school services. Along with these needs, they also require more attention and time from their caregivers.²³ It has been observed that most of these requirements are fulfilled by the mothers only and that makes them overburdened and stressful. Therefore, tangible (financial) and intangible (emotional) support by family and near ones help to decrease the burden of care, depression and suicidal ideation.^{24,25}

Future studies should explore more socio-demographic and other factors playing a role in the burden of care and suicidal ideation of mothers with ASD children.

Conclusion

The burden of care of mothers as caregivers of ASD children leads to suicidal ideation among them. However, these negative effects can be effectively dealt by providing proper care and social support to the mothers.

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