Perceived Stigma, Social Support, Care giving Burden and Marital Adjustment among Mothers of Children Diagnosed with Autism Spectrum Disorder

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The purpose of this correlational study was to identify the relationship of perceived stigma, social support, caregiving burden and marital adjustment among mothers having children diagnosed with Autism Spectrum Disorder. It also investigated the predictors of marital adjustment and mediating role of caregiving burden between the relationship of perceived stigma and marital adjustment among mothers of children having ASD. Total of 100 mothers aged between 24-55 years (M= 36.55; SD= 6.57) participated in this study. Data was analyzed using Pearson Product Moment Correlation Coefficient, Multiple Hierarchical Linear Regression and PROCESS by Hayes (2018). Results revealed low social support and high caregiving burden were significantly related with low marital adjustment among mothers. Family support emerged as a significant positive whilst friends support and caregiving burden as negative predictor of marital adjustment. Mediation analysis showed caregiving burden to fully mediate the pathway between perceived stigma, social support and marital adjustment. This study has implications for mental health practitioners, social workers and government to develop awareness and public policy for parents of special children.

Keywords: Burden of Caregivers, Social Support, Marital Adjustment, Stigmatization, Autism Spectrum Disorder.

Autism Spectrum Disorder (ASD) is a lifelong mental condition which includes persistent impairments in social skills, language and activities of the person which leads to a stressful situation for the primary caregivers especially mothers of the child (Furrukh & Anjum, 2020). The estimated number of autistic children in Pakistan is 1 out of 120 (Anwar, et al., 2018). The prevalence of ASD is rising globally, even in Pakistan the approximate number of children with ASD is 350,000 (The Nation, 2012). Primary caregivers of children of ASD children experience anxiety, stress and strong pressures from society (Bitsika & Sharpley, 2017). Raising a child with special needs itself is an ordeal as it demands additional physical and emotional resources; parents taking care of ASD child report high stress as compared to parents of children with no disabilities (Giovangoli et al., 2015; Kiami & Goodgold, 2017; Furrukh & Anjum, 2020). Mothers having children with physical or psychological disabilities undergo agonizing stress during the diagnosis of their child and even after diagnosis which is linked with low levels of social support from the family and society particularly in south Asian countries (Khan, et al., 2020). Most of the husbands in the Asian region are hesitant to give the cost of treatment of disabled children, which includes the cost of therapy process and medications. This may lead to deterioration of mental health in the mothers (Ahmed & Sanauddin, 2016).

Stigmatization in the past has been studied with reference to mental disorders and has been

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defined as blame, social judgment and rejection from the society on the basis of mental disorder (Weiss & Ramakrishna, 2006). Stigma refers to the direct impact of social judgment on the person whereas perceived stigma is characterized as the reaction that is expected from others (Angermeyer, et al., 2014). Stigmatization of people who suffer from mental health issues has been a major concern (Kermode, et al, 2009). Lack of social support and perceived burden between the mothers of special children can be the foremost determinant of stress, and depression and may lead to suicidal ideation (Ezzat, 2017; Siedlecki, et al., 2013).

Kwok et al. (2014) showed a significant association between marital satisfaction and perceived stigma among mothers having children with ASD. Moreover, significant impact of the mediating role of perceived care giving burden with perceived stigma and marital satisfaction was also observed. Further, social support increased the marital satisfaction of the couple and reduced the perceived stigma among caregivers of children with ASD. Caregiving burden may result in different psychopathological symptoms depending upon the type of psychopathology of the patient that they are looking after (Ghanizadeh, et al., 2009; Tamizi et al., 2019). For example, when looking after children with ASD, the caregivers may experience melancholic personality, persistent depression and negativism (Amiri, et al., 2016). Sim et al. (2017) study showed high care giving burden experienced by the mothers to be significantly related with low marital adjustment whereas, low parental stress was found associated with increased use of positive dyadic coping strategies such as supporting each other in daily tasks, communicating empathy, joint problem solving, sharing feelings and mutual commitment. Couples using dyadic coping strategies were found to be well adjusted in their marital relationship and dealt well with the challenges of raising an ASD child positively.

The process of the appraisal of the stressor as desirable or undesirable plays a role on the social functioning or the well-being of the care giver (Lazarus, 1991; Lawton, et al., 1991). The appraisal of the caregiver's burden might also operate as a mediating variable for the relationship between the stressors of caregiver and the marital adjustment (Kwok, Leung & Wong, 2014). The tasks of care giving are usually described as direct stressor but for parents of children having disabilities these tasks are described as indirect in the form of stigma that is received from other people (Furrukh & Anjum, 2020). Weiner's (1993) attribution theory explains that the way an individual assigns to the cause of a particular disorder can affect the behavioral reaction of that individual towards the person having the particular disorder. Attribution analysis explains that people have an urge to find the cause of everyday events. So, they have this underlying motivation to find as to why a certain person is suffering from a mental disorder and as result, they may connect a negative connotation to people having mental disorders have decreased competence to deal with their everyday problems and have low self-control thus they suffer from a mental disorder (Ryan, 2007).

Kwok et al. (2014) reported that perceived care giving burden and perceived stigma significantly predicted marital satisfaction of the ASD mothers in China. The mediation analyses showed that perceived caregiving burden significantly mediated between perceived stigma and marital satisfaction which explains that greater caregiving burden led to high perception of stigma and low marital satisfaction. Khusaifan and Keshky (2020) in their cross-sectional study to assess the impact of social support as a mediator and/or a moderator between parental stress and life satisfaction among parents of children with ASD in Kingdom of Saudia Arabia showed high perceived family and parental stress to be related with low life satisfaction, and this relationship

was lower when mediated by social support. Social support moderated the relationship between family stress and life satisfaction which explains that greater social support led to low family stress and greater life satisfaction.

Rationale and Significance of the Study

Raising up a child with disability is a very stressful experience for the caregivers, who are usually mothers. In spite of increased awareness about the mental health issues there is still much room to work on stigma attached to the mental disabilities. The caregivers undergo immense burden while taking care of a mentally challenged child and require a great deal of time to take care of such children which leaves them with little time for other activities such as giving time to their spouse and other leisure activities. This creates problems for the caregivers in their marital life and spousal relationship because husbands also demand time and attention which the mothers having children with disabilities are able to provide. According to the attribution model the method through which the parents internalize their stigma based on the stigma they experience for having children with autism. It shows that the parents directly internalize courtesy stigma through self-blame, perceived responsibility and perceived controllability. The parents believed that they easily associated to the negative views attached to them and their autistic children and through this they blamed themselves for having such children and attributed this responsibility on themselves. This rare combination of variables is not used commonly in previous researches consequently this study may help bridge the gap between the literatures particularly in reference to south Asian countries. It aims to benefit the society at large by targeting those caregivers which have mentally challenged children. This study emphasizes on the need of social support to deal with the burden of care givers. This study will be a stepping stone towards highlighting the stigma attached to mentally challenged children and may prove helpful in minimizing adverse behavioural reactions which are displayed by the society towards such children and their care givers. Hence the objective of the study is to check the relationship of perceived stigma, perceived social support, burden of caregivers and marital adjustment among mothers of children diagnosed with autism and to see the mediating role of care giving in relation with perceived self-stigma and social support on marital satisfaction among mothers of children with ASD.

Method

Research Design

For present study, co relational research design was used to study the relationship of perceived stigma, social support, care giving burden and marital satisfaction among mothers having children diagnosed with autism spectrum disorder.

Participants

A purposive sample was calculated by employing G power. The sample of 100 mothers having children with ASD age ranged from 24 to55 years (M= 36.55; SD= 6.57), was collected from six different institutions for special needs children during Covid19 pandemic. Data was collected in person and online. The inclusion and exclusion criteria for the participants is given below:

Inclusion Criteria

- Mothers having children diagnosed with ASD by a practicing clinical psychologist or psychiatrist were included.
- Only those ASD children who were enrolled in a special education institution were included.

Exclusion Criteria

- Mothers who are divorced, widowed or separated were excluded.
- The ASD children who have received the diagnosis but are not enrolled in a special education institute were not included.

Measures

Following measures were used in the current study:

Demographic form

A self-constructed demographic form was used to gather demographic information from the participants regarding age of the caregivers, gender, and education of caregiver, family system, occupation, and number of children, type of disability, birth order of child and age of child.

The Parents Self Stigma Scale

The Parents Self Stigma Scale measures self-stigma of parents using 11 items on a five-point Likert Scale with 1 to 5 from *Never to almost all of the time*. The highest score is 55 and the lowest possible score is 11 with high score indicating greater self-stigma. The internal reliability value is 0.88 (Eaton, et al., 2018).

The Multidimensional Scale of Perceived Social Support

Scale measures perceived social support using 12 items on a 7-point Likert scale with a minimum rating 1 (*very strongly disagree*) to 7 (*very strongly agree*). The highest score is 49 and lowest is 7. It has three subscales: Significant Others Subscale; Family Subscale and Friends Subscale. The reliability value of this scale is 0.92 (Zimet, et al., 1988).

Zarit Burden Interview

It measures the experience of caregiver burden using 22 items on a 5-point Likert scale with a minimum rating 0 (*never*) to the maximum rating 4 (*nearly always*). The score ranges from 61 to 88, low score connotes low burden; Cronbach alpha value for ZBI is 0.93 (Zarit, et al., 1980).

The Locke-Wallace Marital Adjustment Test

This scale measures the level of marital adjustment by means of 15 items using a 6-point Likert Scale, with a minimum score of 1 (always disagree) and maximum score of 6 (always agree). The highest score is 158, high score means high marital adjustment. Internal consistency value of reliability is 0.90 (Locke & Wallace, 1959).

Procedure

A pilot study was conducted which showed no major problem reported by the participants, however 5% mothers were reluctant to fill the questionnaires. Institutional authorities were briefed about the aim of study. Participants were administered questionnaires either in person or online due to Covid19 lockdown; 10-12 minutes were approximately taken by the participants to fill in the questionnaires. One time approach to participants was used. The permission of tools and data collection was sought from the concerned authorities. The authorities of the institution for mentally challenged children were informed about the purpose and procedure of the study. Volunteer participation was done. The nature and purpose of the study was explained in detail to subjects. No physical or emotional threat was there for participants. However, they were assured that their identity would not be revealed and it will remain confidential and that their responses will only be used for the research purpose. They were also told about their right to leave research at any point in time.

Results

Table 1

Psychometric Properties of Major Study Variables in the Sample (N = 100)

Variables	*k*	*M*	*SD*	*Range*	*α*	*Skewness*	*Kurtosis*
PSSS	11	26.06	6.14	11-55	0.68	4.07	1.35
MSPSS							
Significant Others	4	17.91	6.49	4-28	0.90	-1.45	-1.97
Family	4	18.69	7.02	4-28	0.91	-1.76	-1.74
Friends	4	17.33	6.33	4-28	0.84	0.80	-2.46
ZBI	22	42.54	18.88	0-88	0.94	2.13	3.80
LWMAT	15	78.85	23.67	2-158	0.61	1.28	-1.45

Note. k = total number of items, α = Cronbach's alpha, M = Mean, SD = Standard Deviation, PSS = Parents Self Stigma Scale, MPSS = Multidimensional Scale of Perceived Social Support, ZBI= Zarit Burden Interview, LWMAT = Locke-Wallace Marital Adjustment Test.

Above mentioned table showed that skewness and kurtosis values of all four scales fall within the acceptable range according to the central limit theorem which states that by the time the sample size reaches 30 the distribution is almost perfectly normal (Gravetter & Wallnau, 2017). The result of reliability analysis indicated that the Cronbach's Alpha values of all four scales followed average to excellent reliability of scales used in this study. A general accepted rule is that α of 0.6-0.7 indicates an acceptable level of reliability, and 0.8 or greater a very good level (Hulin, et al., 2001).

Table 2

Correlation for Parent's Self Stigma, Social Support, Caregiving Burden and Marital Adjustment among Mothers having Children Diagnosed with Autism Spectrum Disorder (N=100)

Measures	*M*	*SD*	1	2	3	4	5	6
1.PSSS	2.37	.56	-					
2.SO	4.48	1.62	-.30**	-				
3.Family	4.67	1.76	-.37***	.77***	-			
4.Friends	4.33	1.58	-.33***	.72***	.73***	-		
5.ZBI	1.93	.86	.37***	-.18*	-.15	-.30**	-	
6.LWMAT	5.21	1.61	-.30**	.39***	.49***	.31**	-.37***	-

Note. PSSS= Parent's Self Stigma Scale, SO= significant other, ZBI= Zarit Burden Interview, LWMAT= Locke Wallace Marital Adjustment Test.

Table indicates a significant negative relationship of perceived self-stigma and caregiving burden with marital adjustment and significant positive relationship of significant other support, family support, and friends support with marital adjustment. The results indicated that there is significant negative relationship of perceived self-stigma and caregiving burden with marital adjustment. This means that when perceived stigma and caregiving burden increases, the likelihood of marital adjustment decreases among mothers having children diagnosed with autism spectrum disorder. The results also indicated that there is significant positive relationship of significant other support, family support, and friends support with marital adjustment. This means that when support increases then marital adjustment also increases among mothers having children diagnosed with autism spectrum disorder.

Table 3

Multiple Hierarchical Linear Regression showing Occupation, Perceived Stigma, Social Support, Caregiving Burden as Predictors of Marital Adjustment among Mothers having Children with Autism Spectrum Disorder (N=100)

Predictors	B	95% CI		SE B	β	R^2	ΔR^2
		LL	UL				
Step I						.06*	.06*
Constant	5.93	5.30	6.60	.32	---		
PO	-.50	-.85	-.10	.19	-.24*		
Step II						.16***	.10**
Constant	8.00	6.62	9.40	.70	---		
PO	-.40	-.76	-.03	.18	-.21*		
Perceived Stigma	-.91	-1.46	-.36	.28	-.31**		
Step III						.30***	.15**
Constant	5.18	3.22	7.13	.10	---		
PO	-.21	-.56	.15	.18	-.11		
Perceived Self Stigma	-.52	-1.07	.03	.27	.18		
Significant Others	.06	-.25	.37	.15	.06		
Family	.43	.13	.74	.15	.48**		
Friends	-.16	-.44	.12	.14	-.16		
Step IV						.39***	.08**
Constant	5.78	3.90	7.66	.95	---		
PO	-.17	-.51	.17	.17	-.08		
Perceived Stigma	-.13	-.70	.44	.30	-.04		
Significant	-.00	-.30	.30	.15	-.00		
Family	-.56	.26	.86	.15	.62***		
Friends	-.30	-.57	-.01	.14	-.29*		
Caregiving Burden	.70	-.10	-.30	.20	-.34**		

Note: CI= Confidence Interval, LL= Lower Limit, UL= Upper Limit, *p<.05. **p<.01 ***p<.001. PO = participant's occupation.

Table 3.3 shows that assumption of independent errors was met as the value of Durbin Watson was between the acceptable range of 1 and 3. The assumption of no perfect multicollinearity was tested by checking the tolerance values and the assumption was met because all the values were greater than 0.2. The assumptions of homoscedasticity, linearity and normally distributed errors were also met.

In Model 1, occupation was entered as the predictor variable and regression model was significant, $R^2 = .06$, $F (1, 95) = 6.05$, p<.05. In model II, stigma was entered as the predictor variable with occupation and the regression model turned out to be significant, $R^2 = .16$, $F (2, 94) = 8.79$, p<.001. When the effect of model I was excluded from model II, model II still remained significant, $\Delta R^2 = .10$, $F (1, 94) = 10.90$, p<.01. In model 3, three dimensions of social support i.e.

significant other, family and friends were entered as predictor variable with occupation and perceived stigma and the regression model turned out to be significant, $R^2 = .30$, $F (5, 91) = 7.99$, $p<.001$. When the effect of model 2 was excluded from model 3, model III still remained significant, $\Delta R^2 = .15$, $F (3, 91) = 6.44$, $p<.01$. In model 4, caregiving burden was entered as the predictor variable along with occupation, stigma, 3 dimensions of three dimensions of social support i.e., significant other, family and friends and the regression model turned out to be significant, $R^2 = .39$, $F (6, 90) = 9.46$, $p<.001$. When the effect of model III was excluded from model IV, Model IV still remained significant, $\Delta R^2 = .08$, $F (1, 90) = 11.98$, $p<.01$.

Among all predictors, family support emerged as significant positive predictor of marital adjustment among mothers having children diagnosed with autism spectrum disorder. Friends and caregiving burden emerged as significant negative predictors of marital adjustment among mothers having children diagnosed with autism spectrum disorder.

Mediation analysis were done with the purpose of finding the mediating role of caregiving burden on the relationship between mother's occupation, perceived self-stigma, three domains of social support i.e., significant other, family, friends and marital adjustment. Mediation model of four domains is shown below (figure1-4) where βc indicates the predictive value of an independent variable before implementing the mediator and βc' refers to an independent variable after implementing the mediator.

The assumption of continuous measurement was checked and all the scales were measured on continuous scale. The assumption of normality was checked through skewness and all the values lied between the ranges of +2.58 to -2.58. The assumption of linearity was tested by regression model and the relationships among the independent and dependent variables were linear, so this assumption was also met.

Figure 1

Caregiving Burden as Mediator between Perceived Self-Stigma and marital adjustment.
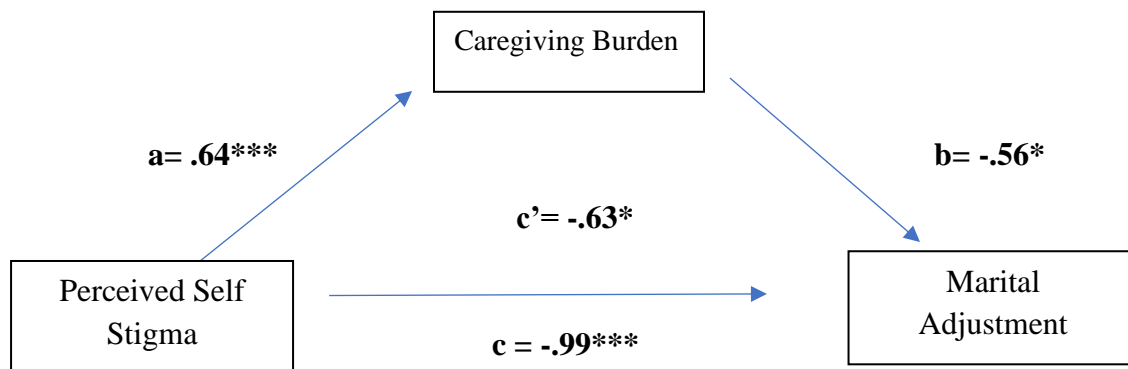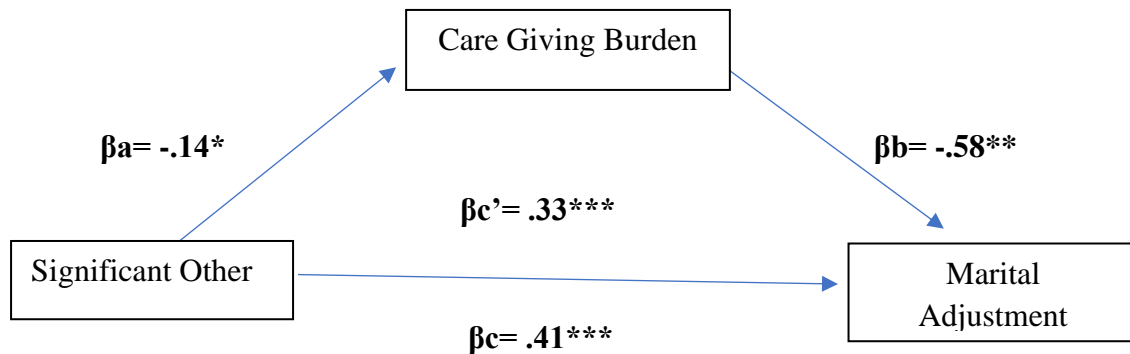

The figure shows the model of relations between perceived self-stigma, caregiving burden and marital adjustment. a, coefficient between independent variable and mediator (indirect effect), b, coefficient between mediator and dependent variable (indirect effect),c, coefficient between dependent and independent variable (total effect),c', coefficient between dependent and independent variable (direct effect). There was a significant indirect effect of perceived self-stigma on marital adjustment through caregiving burden ab= -.12, BCa CI [-.23, -.02].
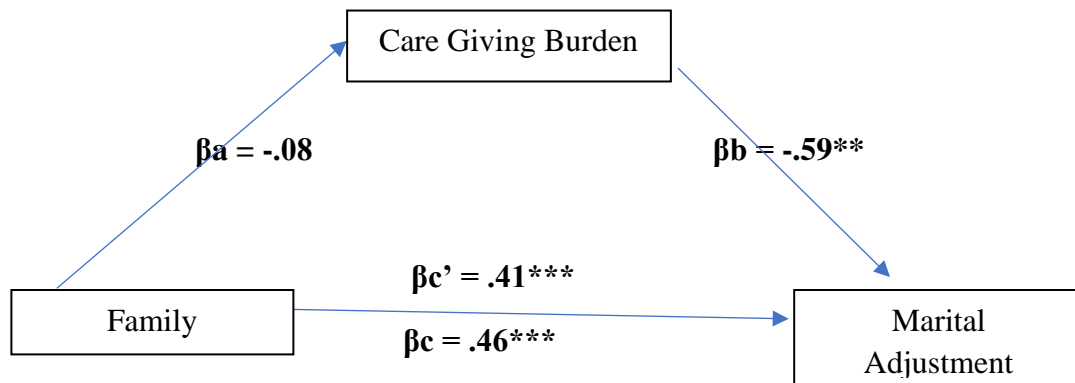
Figure 2

Caregiving Burden as Mediator between Perceived Social Support (Significant Other) and marital adjustment.

The figure shows the model of relations between one dimension of social support i.e. significant other, caregiving burden and marital adjustment. There was a significant indirect effect of significant other on marital adjustment through caregiving burden ab = .08, BCa, CI [.01, .16].
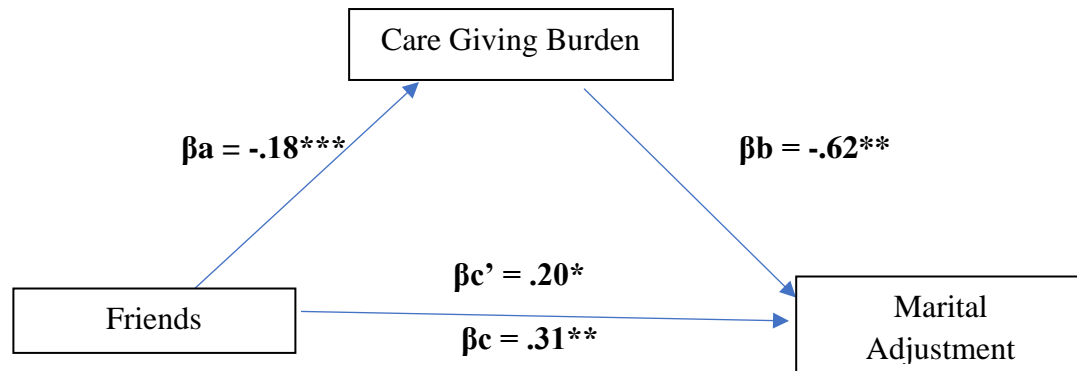
Figure 3

Caregiving Burden as Mediator between Perceived Social Support (Family) and marital adjustment.

The figure shows the model of relations between one dimension of social support i.e. family, caregiving burden and marital adjustment. There was a non- significant indirect effect of family support on marital adjustment through caregiving burden, ab = .05, BCa CI[-.01, .12].

Figure 4

Caregiving Burden as Mediator between Perceived Social Support (Friends) and marital adjustment.

The figure shows the model of relations between one dimension of social support i.e. friends, caregiving burden and marital adjustment. There was a significant but indirect effect of friends support on marital adjustment through caregiving burden ab= .11, BCa CI [.03, .20].

Discussion

Results revealed significant positive relationship of social support with marital adjustment among mothers of children diagnosed with ASD. In line with our present findings, Benson (2019) reported that mothers of ASD children who received more support from their spouse and family reported higher quality of marital life and also reported to have better marital adjustment. Significant negative relationship was reported of perceived self-stigma and care giving burden with marital adjustment among mothers of children diagnosed with autism spectrum disorder. Dey and Amponsah (2020) examined three sources of perceived social support and its effect on resilience among parents from Ghana, having children with special needs. It also studies the impact of having social support as protective factor for resilience which in return helps the parents among their own relation and to have better martial satisfaction. It was found out that having support from significant other had significant positive relation with resilience. And married couples had more resilience as compared to single parents. So the results from this study showed that married couples who received support from their significant others and not family and friends, had the ability to better cope with stressors while raising their child with special needs. In cultures like, Ghana, which are interdependent, depend greatly on social networks for support and share strong bonds among each other, for them social support is significant in the general functioning of individuals living in those cultures. Results from our study and in coherence with the results from this study as Asian culture just like Ghanaian culture is also mutually supporting and people here tend to rely on social support from their family or significant others in times of happiness and worry. So, support from significant other is important while raising a child with disability in order to cope well with the stressors and also to maintain a healthy relation between the husband and wife.

The results of regression analysis showed that family support emerged as significant positive predictor of marital adjustment among mothers having children diagnosed with autism spectrum disorder explaining 62% variance in the results. This suggests that in mothers having

children diagnosed with autism spectrum disorder who had family support are more likely to have marital adjustment. Friends and caregiving burden emerged as significant negative predictors of marital adjustment among mothers having children diagnosed with autism spectrum disorder explaining 29 % and 34% variance respectively. This suggests that in mothers having children diagnosed with autism spectrum disorder who had friends support and caregiving burden are less likely to have marital adjustment.

Perceived self-stigma, social support and caregiving burden predict marital adjustment among participants as in line with our results according to Lei and Kantor (2021) study of Chinese families revealed that having social support increases the family cohesion and adaptability in taking care of the child with ASD which comes with a lot of responsibilities and burden's. Having support from the family increases helps in taking care of the child with ASD and reduces the burden of the parents by strengthening their own quality of life. Again, similarities in Chinese and Asian culture can be seen as an embodiment of perceiving social support as a backbone of family strength and increasing the quality of life of parents raising children with disability. In line with our present findings, McIntyre and Brown (2019) study to examine the utilization and usefulness of social support for mothers in America having children with autism spectrum disorder, family support emerged as a significant positive predictor showing 21% variance in the results. This means that mothers having children with ASD utilize more social support and among them, family support is the most valuable predictor in taking care of the child with ASD.

In America, the culture and family values do not hold much significance as compared to Asian culture but American culture is also influenced by the Asian and other cultures hence the similarity in results that caregivers from Western culture also give importance to family as a pillar of support when it comes to raising a child with disability. Marsack and Church (2019) carried out a study on the caregivers of adult children with autism from Michigan, to investigate developmental, emotional, time and financial burden of the caregivers and its impact on their quality of life. Regression analysis showed that developmental burden emerged as strong negative predictor of quality of life of the caregivers. It was observed that developmental burden, the burden of feeling isolated from the peers and social support group because of having a child with disability and receiving minimum or very less support from the social network explained 35% variance in the results. This means that those who experienced less caregiving burden had high quality of life and vice versa. These results are in line with our study showing that no matter what the age group of children, the caregivers still perceive burden when raising a child with disability and they need social support from their peers and family in order to have a better quality of life.

In current study, care giving burden mediated the impact of perceived self-stigma and social support on marital satisfaction among participants. Li, et al. (2019) investigated the links between maternal caregiving burden and marital and child adjustment and found out whether these links were mediated by maternal coping strategies and social support. The results of this study showed that social support and maternal coping strategies mediated the impact of maternal caregiving burden with maternal life satisfaction. Similar to our findings, this study also shows significance of social support to mediate the impact of caregiving burden and life satisfaction.

Conclusion

The findings of the study highlighted strong positive relationship of social support with marital adjustment and strong negative relationship of perceived stigma and caregiving burden

with marital adjustment. Present study attempted to find significant predictors of marital adjustment and the findings showed that two dimensions of social support (i.e. family and friends) and caregiving burden emerged as significant predictors of marital adjustment. The study also found the mediating role of caregiving burden on perceived self-stigma and social support with marital adjustment .The findings can be used to understand the difficulties faced by caregivers of children who are mentally challenged, to provide them with social support and to end the social stigma that they face while raising such children.

Limitations and Suggestions

Demographics were effectively controlled in the study but they did not show any relation and therefore did not play any role in predicting marital adjustment except the occupation of the mother. The tools used in the sample were only used in English language. Bilingual sample data collection must be preferred, native Urdu language tools must be used so that they are understandable by the population easily. Data should be collected from both urban and rural areas so that the results can be more generalizable.

Implications

The findings of this study are beneficial for mental health practitioners and social workers so that they create an environment in which the caregivers feel less burden and to teach various coping methods to the caregivers especially mothers to cope with the stigma and negative reactions received from the society. Techniques like support groups, counselling sessions which include telling about techniques like meditation and learning more about the disability, communicating well with their significant other about the problems faced while raising a child with disability can help in providing counselling to the caregivers. This study adds to the indigenous literature based on the caregivers having children diagnosed with autism spectrum disorder.

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