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Impact of husband's social support for mothers of children with autism in India

Manisha Choudhury

Ph.d Scholar (Allied and Behavioural Sciences), Amity School of Allied and Behavioural Sciences (AIBAS), Amity University Rajasthan, SP-1, Kant Kalwar, RIICO Industrial Area, NH-11C, Jaipur, *Rajasthan*, India

Corresponding author email: manishachoudhury3119@gmail.com

Dr. Payal Chandel

Associate Professor, Department of Psychology, Central University of Haryana

Email: paayalchandel@gmail.com

Abstract--- Aim of the study: The main aim of the study is to investigate husband's social support for mother of children with autism. Method: Interview was conducted for 20 mother participants who were married and having children with autism aged between 4-15 years. Data collected was analyzed by using interpretative phenomenological analysis (IPA) approach. Results: The data analysis was divided in five domains. First, the impact on marriage relationship; second, husband's role in parenting children with autism; third, mother's perception regarding husband's social support; fourth, indicated factors influencing husband social supports; and fifth the result explored the effect of husband's social support for mother. The discussion and limitations of the present study has been considered. Application: The findings highlight the areas for rehabilitation professionals who should also focus on the relationship of parents for better improvement of the child and family.

Keywords---Husband, Mother, Autism, Social Support, Parent-child relationship.

Introduction

Every parent in this world don't want their children to be born with disabilities or limitations. Every individual desire to be fully independent without any kind of physical limitation or disability (Desiningrum, 2016). In any situation if parents come to know that their child has limitations, the general reaction which comes in them is usually in the form of either sadness, frustration, grief, disappointment,

feeling of guilty, rejection, angry before they can accept their child with the same (Lyons et al., 2010). As per the current trend, wherein both father and mother are working in a developing country like India, the most common developmental disorder that has led to high stress and depression among parents is autism spectrum disorder (ASD). Autism is a type of neurodevelopmental disorder that often gets diagnosed in the first 3 years of age. Children diagnosed with autism generally exhibit delayed communication skills with inability to control their behavior and social interaction (Desiningrum, 2018). The global burden of autism is not known. Almost all the studies conducted since 2000 across diversified geographical regions of the world indicate a prevalence rate of 17/10,000 for autistic disorder (Ekas et al., 2016) With respect to Indian Scenario, prevalence of autism and autistic traits is very high among pediatric population (Sun & Allison, 2010). Expected estimates mentioned across numerous studies in UK and USA suggest that India might have more than 2 million people with ASD (Karaer, 2019). Although, there is dearth of studies regarding Indian ASD prevalence (Mann et al., 2013). Some studies based on hospital set and small-scale studies have been conducted which have reported varying estimates regarding the prevalence of autism in outpatient samples based on psychiatric department data which varies from 2.9% to 62.5% (Mann et al., 2013)

Based on similar studies, it's evident that parents of children with ASD tend to experience greater levels of depression, anxiety and stress in comparison to parents of children with other developmental disorders (Etournaud, 2017; Petrongolo, 2014). Studies have highlighted the possible factors related to increased stress levels among parents of children with ASD which is related child's behavioral issues (Blacher & McIntyre, 2006), deficit speech and language skills affecting communication, academic/ difficulties of the child with ASD (Bebko et al., 1987), and the situations created due to child's behavioral issues often trigger conflict in marital relationships (Hartley et al., 2010). In general, the role of a mother is deeply rooted to tasks like proper nurture and care of the newborn (Santrock, 2018). In a study conducted by Ozturk et al. (2014) revealed that most of the parents especially mothers of children with ASD found to be exclusively associated in social behavior with their children in comparison to fathers. Similar study performed by Rosa et al., (2021) indicated that mother's mental health had a significant impact on child's mental development. Mother's psychological wellbeing is directly related to family support, professional guidance and awareness about autism among family networks (Rosa et al., 2021). The influence of parenting style and mother's mental health from mental health in children who have siblings with autism). In the current study researchers basically focused on mothers of children with ASD who are highly susceptible to parenting stress.

With respect to caring of children with ASD, it's difficult for mothers to perform both parenting and household chores alone without social/family support, which in absence results in high stress and depression. An ecological model of family was formulated by a group of researchers which places the mother at the center of the environment surrounded by spouses, children, extended family and friends, or friends; with whom the individual can interact a lot. With respect to mothers of children with ASD, family support seems to be most important and is assumed to be obtained extensively from husband (Greenlee et al., 2018).

Evidence from previous studies also focus on the notion that family support regarding childcare with ASD can improve mother's psychological well-being, and this family function/support can be provided from spouses, siblings of child or extended family members (Desiningrum et al., 2018).

Similar study was done by Johnson et al. (2011), the results revealed that better the support received by the mother's family specially husband who are parenting children with ASD, the more positive reaction has been noticed in mother's behavior regarding acceptance of the child. Thus, from the above-mentioned studies, it can be concluded that the objective of the current study is regarding the various forms of husband's social support and the how these various forms of social support are perceived by mothers caring children with ASD and also the associated factors which impacts mothers social support from husband.

Method

In the present study qualitative method with a phenomenological approach was implemented. The qualitative methodology aims to elaborate the appropriate experiences with the participants included in the current study. There have been studies which has provided relevant results based on qualitative approach (Smith et al.,2009). In this research mainly interpretative phenomenological analysis was used which has two stages. The first stage basically delas with the subject interpreting life instances, whereas in the second stage, the examiner analyzes and interprets the result obtained regarding the participant's experience which is usually considered as double hermeneutics.

Participants

Participants considered for the study were 20 mothers of children aged within 5-14 years diagnosed with ASD and staying with their husband in a family. All respondents are domiciled within the state of West Bengal, India.

Procedure

Participants for the present study were selected by using purposive sampling technique. Informed consent was obtained for the detailed interview phase. Semi-structured interviews were framed which usually lasted for 60 min. Based on the interview in the clinical setting the following data was extracted:

- 1) Experiences and problems faced by parents dealing with children with ASD and its impact on martial relationship,
- 2) Mother's perception regarding role of husband and analysis of mother's expectations for social support from her husband.
- 3) Mother's perception regarding role of husband in providing social support and its significance on development of the child and respective families.
- 4) Interviews which were conducted were recorded, transcribed followed by detailed analysis.

Data Analysis

Data analysis of sociodemographic description regarding the participants is mentioned in Table 1 and Figure 1. Data collected reveals that majority of participants (Figure 2) belong to housewife category followed by other professions due to which it is expected that impact of husband social support plays a major role in this category. After the detailed transcription, the collected data was analyzed using interpretative phenomenology analysis (IPA) in order to identify the themes and specific patterns in the data being analyzed. IPA analysis was divided into four stages:

- 1) Repeated reading of the transcript and deeply analysis the meaning pf the information collected.
- 2) Provide necessary comments in either descriptive, linguistic or conceptual comments on the utterances of the participants.
- 3) Developing a related sub domain theme,
- 4) Establishing patterns between participant's transcripts, and
- 5) Describing the main theme regarding the factors associated with the relationship of husband and wife of children diagnosed with autism.

Table 1
Sociodemographic Details of Participants

Category	Total
Age	
20-22	04
23-40	12
41-50	02
Work/profession	
Government employees	3
Private firm employees	4
Self-employed	6
Housewife	7
Age of children	
05-11 years old	14
12-14 years old	6
Severity of Autism	
Minimal	8
Moderate	7
Severe	5
Gender of Children diagnosed with ASD	
Male	12
Female	8

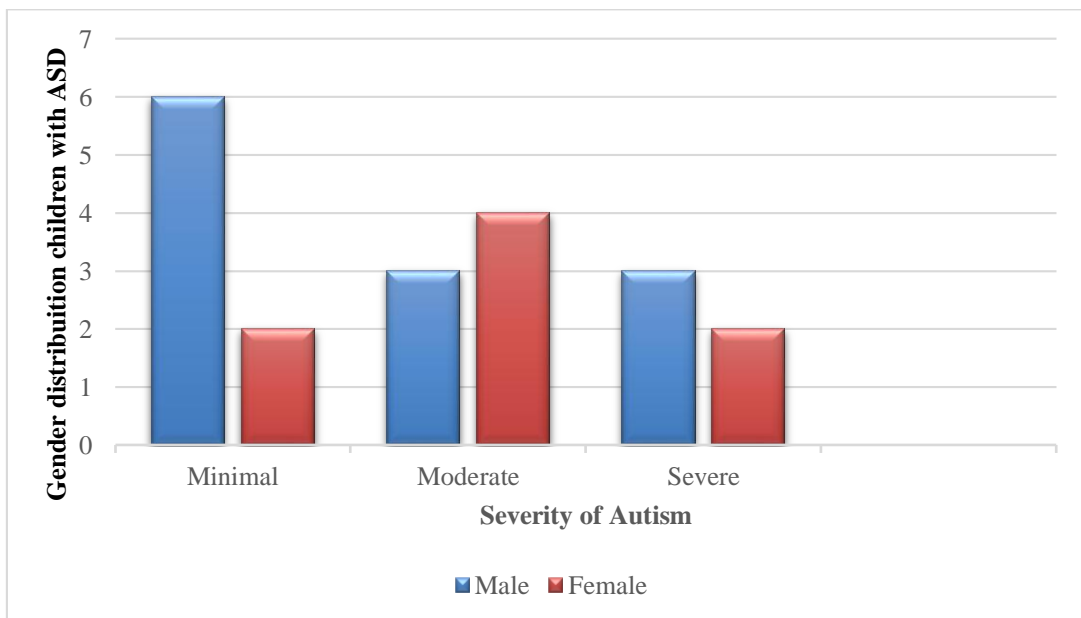


Figure1: Graph showing the distribution of children based on gender across the spectrum of ASD.

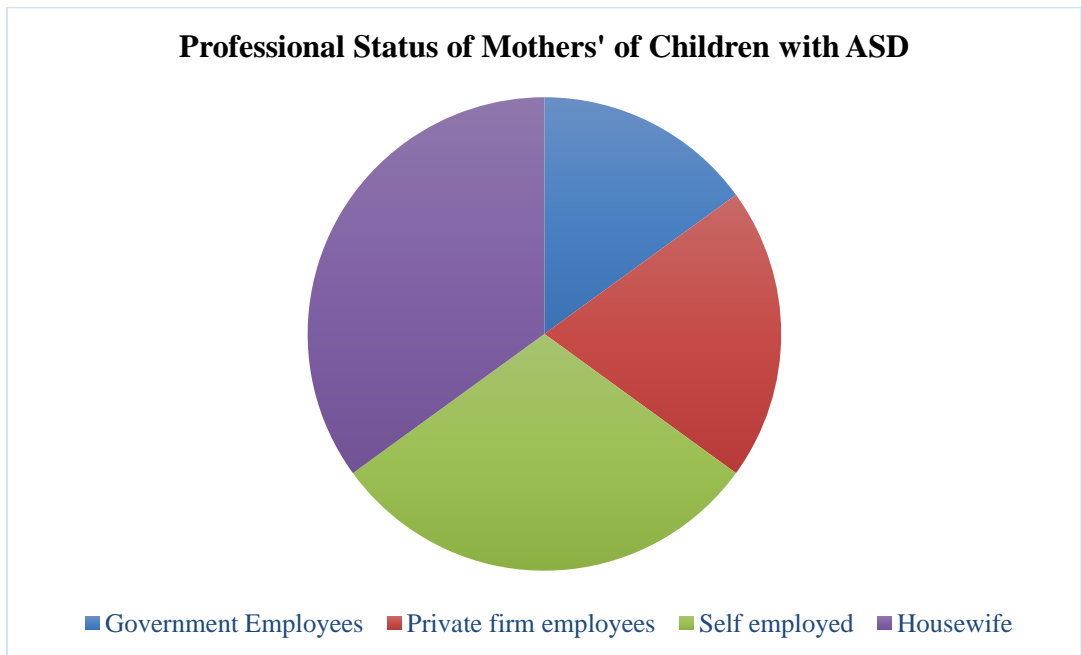


Figure 2: Pie-chart showing the professional status of mothers participated in this study

Results

As per the analysis, mothers have discussed their respective hopes and perceptions with open minded approach, their individual experiences regarding caring and educating children with ASD, the various barriers in the society, support expected from husbands; based on which five domains and subdomains as mentioned in Table 2.

Table 2
Themes and Sub-themes of Parents parenting child with ASD

Core Domain	Sub-Domain
I. Impact on martial relationships on wives dealing with children with ASD	<ul style="list-style-type: none"> • Any kind of communication Disorder among children triggers mis-communication between husband and wife. • Child's behavioral issues has a negative effect on martial stress tantrum behavior stimulates marital stress. • Cognitive abilities of child diagnosed with ASD mostly results in marital stress and divorce. • Some parents mentioned proper education and therapy efforts results in better martial relationship
II. Role of fathers during parenting their child diagnosed with ASD.	<ul style="list-style-type: none"> • Interested in participating seminars related to ASD. • Minimal involvement of husband in parenting child with ASD. • Care and affection for children with ASD.
III. Perception of mother regarding husband's social support.	<ul style="list-style-type: none"> • Contribution in emotional support. • Support during feeling of low-esteem. • Informative and instrumental support. • Providing substantial support in family and society
IV. Factors affecting husband's social support.	<ul style="list-style-type: none"> • Individual Attitude and character. • Educational qualification. • Professional status. • Socio-economic status of family. • Support from other siblings. • Existence and impact of extended family members behaviour at home.
V. Impact of husband's	<ul style="list-style-type: none"> • Reduce the burden of mother's

support on mother mental health regarding the development of child diagnosed with ASD.

stress by sharing parenting of child with ASD.

- Without husband's optimal social support, parenting a child with ASD is not possible for a mother.
 - Establishment of healthy relationship among extended family members.
 - Maintaining a good quality of life and family well-being.
-

Discussion and Conclusion

Communication plays a very crucial role in humans to establish an effective social interaction, and maintaining a proper synchrony in communication tends to be difficult for the families dealing with children with ASD (Sim et al., 2019). Present study has investigated several aspects with respect to mother's perception towards husband's existence regarding parenting which includes proper care and education for children with autism spectrum disorder and providing adequate support towards wife. Children diagnosed with ASD tend to exhibit some specific kind of behaviors which includes emergence of echolalia, flapping of hands, hyperactive nature. 17 out of 20 mothers mentioned that their child has delayed speech language milestones as compared to typical developing children or their siblings. The overall characteristics found in the above data reveals that most of the mothers had the concern of limited ability to communicate regarding their child with ASD triggered stress among mother.

Karaer & Akdemir (2019) has mentioned in their study that periodic emotional regulation is highly required so that stress is reduced and doesn't lead to any other associated psychological trauma between husband and wife or as an individual. 15 mothers have accepted and stated that their children have behavioral issues such as hyperactive in nature, difficult to control, self-hurting nature etc. There are supporting studies which have quoted that ASD children exhibit delayed speech milestones, hyperactivity and several other behavioral problems which affects social interaction of child and parents (Walter & Smith, 2016). In this present study, sixteen mothers have reported that due to the severity of ASD, their children were not able to attend regular schools, henceforth they were sent to special schools which affected their social interaction skills and academic growth.

With respect to child's educational and therapy process, most of the participants mentioned that they are either sending their children to special schools or in inclusive schools along with a defined therapeutic regime. Many of them attend various therapy sessions which include occupational, speech, sensory therapy, behavioral and play therapy. Simultaneously, most of the parents have raised their concern that finding both school and therapy center accessible is difficult, as the distance between school and respective centers make their child lethargic and fatigue, resulting poor performance in school or therapy center. As, some of the participants have attended seminars and are aware regarding the need and

role of intensive therapy sessions, therefore, they don't want to compromise the therapy sessions along with schooling. From the above data, it appears that there is virtuous communication between husband and wife regarding parenting a child with ASD which has strengthened the marital relationships.

14 participants have quoted that their husbands usually drop and pick their children at school and respective therapy center. The results of the similar study also indicate that the impact of intensive intervention program in children with ASD was positively correlated with extensive parental involvement and expectations (Shepherd et al., 2018). Sixteen participants expressed their willingness and strong determination towards attending seminars related to ASD. shared that they were diligent in attending seminars related to ASD, and 12 participants stated that they want their husbands also to attend the seminars. of them mentioned that their husbands also wanted to attend the seminar. Studies have revealed that equal involvement of parents in parenting a child with ASD is very important for the overall development the children diagnosed with ASD (Hodgetts et al., 2013). There were ten participants who stated that their husbands were not much involved in parenting the child with ASD. The lack of active participation from husband's behalf as felt by mothers' triggers stress for the mother. On the other hand, there were participants who mentioned that their respective husbands generally discuss issues related to handling ASD child.

In the present study,18 participants out of twenty mentioned that the nature of husband social support received was in the form of cost and accommodation. According to Dutta et al.(2017) therapy and accommodation costs are included in instrumental support. Similar studies have quoted that the expenditure of maintaining education and therapy of a child with ASD is costly for middle income families, and it also includes perseverance and determination for continuing child's therapy sessions along with parental cooperation for better outcome of the child (Chen et al., 2015). The data analysis based upon the interview also focused on the fact that most of the participants expected emotional support and appreciation from their husbands' respectively. The participants also informed that they wanted their husband to be a sympathetic listener who gives some dedicated attention towards their wife and have warm discussion about all the problems of life, a shoulder to lean on when they feel psychological depressed from the routine chores of parenting a child with ASD.

Out of the total population only 6 participants had stated that they received emotional support and constant appreciation from their husbands. Supporting literature review indicates that emotional support and appreciation can play a key role in individual's psychological well-being by avoiding stress and depression (Kayfitz et al., 2010). Meanwhile, thirteen mothers who were working have mentioned that they often feel sad and alone by solitary nature of carrying the burden of child with ASD which is affecting their professional performance, resulting in insomnia and depression. Chen et al., (2015) had quoted in their study regarding the status of mothers' social burden related to stigma and its effect on child with ASD. The researchers found that mothers reported considerable negative social impact which resulted in increased social isolation from friends and extended family, since mothers avoided attending any kind of social activities due child's sudden behavioral outbursts in public and extended

childcare responsibilities. On the other side their husbands are either busy in their respective activities or gives more attention towards the other sibling who is a typically developing child. In other words, the husbands try to neglect the parenting of child diagnosed with ASD. The participants also stated that they often feel emotionally exhausted and always stay in anxiety about the future of the child.

Studies have been done which reveals that the mothers of children who have been diagnosed with ASD will experience any kind psychological trauma or stress if they don't receive adequate support and equal sharing of responsibilities from their partner (Pe´rez-Marfil et al., 2016) The result analysis of the data collected from the interview from the participants focused on the factors which had a strong influence on the level of social support provided by the husband. 12 participants revealed the nature of husbands' support in the form lack of proper attention, considered every discussion regarding the child with ASD as inconsequential due to which it was difficult for the mother to have a detailed discussion with their spouse.

Literature has stated that parental knowledge, attitude and character effect parenting behavior (Crowell et al., 2019). Participants also felt that the work profile of their husbands' and the educational qualification had an impact on their relationship as well observed in parenting their child with ASD. Fifteen participants accepted the notion that post covid pandemic has increased their husbands work load due to which there is always a lack of time on by their husband behalf. On the other side, four participants found that their spouse's tertiary educational qualification gives him the urge to opt for better job opportunities in their career.

Apart from that, the socio-economic status of the family also played a major role in parenting a child, nine of the participants revealed that due to family's limited socio- economic conditions it was difficult for the mother to determine the proper place for schooling and often therapy sessions were missed due to limited financial support from husband. Almost all the participants mentioned that despite of being felt psychologically depressed, they have surrendered to almighty as last hope. Fourteen mothers stated that their children were the best gift for them and kind of smallest social support received from husband is the foremost hope they can expect from their spouse and were grateful for the same.

Numerous studies have focused on impact of individual gratitude leading to positive psychological well-being (Timmons & Ekas, 2018). Almansour et al (2013) had conducted a study on parents of children dealing with ASD, wherein the results revealed higher stress leading to depression among parents dealing with ASD kids compared to communication disorder children or any other typically developing normal child. Six mothers have observed that role of siblings and extended family members of ASD children greatly have an impact on the burden of parenting.

Positive impact is the form of involvement of siblings with ASD children in form of play and accompanying the child with ASD to participate fully in all play-based activities which in turn fulfills the care of mother to make the child with ASD

perform social interactions. As per the results, obtained based on the interview, five participants shared their viewpoint regarding the role of siblings of ASD children and extended family members have a negative effect on husband's behaviors and attitude like showing less concern of caring for ASD child than other siblings or children of extended family members.

During last phase of interview session, all the participants had common viewpoint that there is a high need of husband social support in the form of husband and as a father for child-care with ASD for better outcome of the child and also improving the marital relationship. Eighteen participants have mentioned that a very cooperative and warm husband can reduce the stress of parenting resulting in a healthy relationship and a good quality of life. All the twenty participants accepted the fact that husband's social support can act as a boon for the development of ASD children, because in a child's developmental stage the presence of mother and father play a pivotal role in the emotional growth of the child.

Volling et al. (2009) in their research study had proposed a model based on their research which revealed that fathers have a very critical role in shaping a child's self-control wherein, a child learns to control and their negative emotions. Sixteen mothers had a similar opinion that as a whole, husband's social support results in maintain harmonious relationship in the household chores. The result obtained in the current study and various supporting studies have focused on the finding that if there is equal involvement of husband and wife in parenting their child with ASD, it has a positive impact on marital relationship (Dinisman et al., 2017) and also healthy family well-being (Larson, 2008). In the end of the discussion, the participants mentioned that in addition of reducing parental stress on mothers, existence of husband's role can make all the participants more focused and optimistic towards facing the future.

Thus, from the result analysis the domains which has been extracted are as follows: (1) Impact of child severity of ASD on marital relationship; (2) Role of the father in parenting a child with ASD (3) Perception of mothers towards nature of husband's social support (4) The possible factors which affects husband's social support towards mother and the child with ASD. The implications of the present study is in depth understanding of the maternal experiences and concerns which all the participants have stated during the interview session can serve as a guide to frame and deliver a family centric service layout towards helping parents to identify their specific needs regarding the barriers faced by a mother during parenting a child with autism (Ekas et al., 2016). Family-centered intervention plan can in turn play a crucial role in enhancing the parenting skills and enabling mothers to cope with stressful situations that might be in the form of family or husband burden, thus increasing parent-child attachment by encouraging more love and intimacy among family members also.

Limitations

Though the present study has culminated the possible factors regarding the role of parents in parenting a child with ASD and also focused the psychological well-being of a mother and her expectation as a wife from husband during nurturing a

child with ASD. But still the study has certain limitations, and the results discussed can't be generalized. Some of the limitations are:

- 1) The data collected was from an urban area of West Bengal, India and not from any other state of the country.
- 2) Lack of maternal demographic data and the socio-economic status of the family
- 3) Mothers from rural areas were excluded from the study as they were not interested and the interview was carried out in English.
- 4) Fathers were not directly involved in the current study, henceforth there is a dearth of information regarding their viewpoint with respect to parenting a child with ASD.
- 5) The study was exploratory in nature and hence the results obtained may vary.
- 6) Impact on psychological well-being of mother based upon the severity of autism was not explained in detail.

Future Directions

The result obtained in this study can act as a base for researchers working extensively as psychologists, speech-language pathologists or other rehabilitation professionals who are handling children with ASD resulting in better planning and involvement of parents more in the intervention program for better outcome and healthy quality of life among parents and children. Similar research studies can be conducted by targeting greater sample population and using more standardized test protocols.

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