

Perceived Stress, Social Support, Family Burden and Stigma among Caregivers of Persons with Intellectual Disability

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ABSTRACT

Background: Families of children with intellectual disability often find it difficult to find someone they can trust to look after the child. Caregiver often has to be on hand every minute of every day can therefore become very isolated from other social engagements. This can put on enormous stress on caregivers. Understanding the caregivers' stress, burden, perceived social support and stigma experienced by caregivers of children with intellectual disability is need to assessed and address effectively. **Materials and Method:** The present study was a cross-sectional hospital based study conducted at the outpatient department of a tertiary care teaching institute. Sixty family members of children with intellectual disability were purposively interviewed using perceived stress scale, Perceived Social Support Assessment Scale, Family Burden Interview Schedule and family interview schedule (stigma items). **Results:** Moderate perceived stress among 83% and high levels in 12% of the care giver. Low social support in 50%, moderate in 40%. 41.7% respondents have severe and 56.7% moderate family burden. Mean score of stigma 10.14 with SD \pm 6.11 **Conclusion:** Results indicated that Living with Persons with ID is highly stressful and burdensome. The lack of social support and notion of stigma adds more challenges making it even more difficult for families. Strategies and interventions should target the study variables in order to improve the overall quality of life of both care givers and patients with ID.

Keywords: Perceived stress, social support, stigma, family burden and intellectual disability

INTRODUCTION

Intellectual disability is the inadequate development of intellectual set of skills. (Okan & Özdemir, 2005). It is an important state which causes lifelong deficiencies, affecting each unit in family in almost all aspects and domains such as financial, social, emotional, behavioral and cognitive, and require enduring surveillance, control, care, management and long term process of rehabilitation. (H Çavuşoğlu, 2013). Living and managing a family member having a disability has been identified as a huge task that brings a remarkable stress and burden for the whole family in process of care-giving. Studies from other parts of the world have highlighted that parents been through immense distress and burden, resulting in significant distortion and negative effects on family dynamics. (Banks, 2003; Slope & Turner, 1993). The scenario becomes

worse when it comes to care-giving and management of a person with intellectual disability as the care giving needs demands from initial years of life and will continue to grow more as age advances.

Lazarus and Folkman (1984), worked and developed the theory of stress and coping and highlighted that stress is a two way process where a person actively interact with the environment, not merely those events which may trigger emotional responses (mostly negative). It can be understood that stress is more impactful and affect the person most, when one perceive the situation as taxing and their responses along with resources are insufficient to manage stimulus (behavioral issues of a person with intellectual disability, medical and care giving needs like managing ADLs).

“Social support can be defined as the interpersonal transactions or exchanges of resources between at least two people perceived by the provider or recipient to be intended to enhance the well-being of the recipient.” (SA Shumaker & A Brownell, 1984). It has been evident from review of literature that social support may act as a major shielding and positive factor in preventing and limiting mental health issues and also adds to quality of life. Persons having intellectual disabilities

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(ID) have been recognized to have poor and limited social support. (T Lippold, & Burns, 2009). It has been documented that having social support is a safeguard to both mental and physical illness. Social support is crucial for not only for people having intellectual disabilities but also for care givers. It is obvious that caregivers of persons with ID need social to function and deliver the needs more competently.

The term, family burden, was mentioned first by Grad and Sainsbury. They defined it as the negative expenditures created by the intellectually disabled children for their families. (KR Chou, 2000). Intellectually disabled children significantly affect how their families live. (AJ Houtrow & MJ Okumura, 2011). The roles and responsibilities of family members get changed completely as one of the family members suffering from ID demands high care giving needs. These changes may be related to different areas like intra-familial roles, personal living places, social environments, outlook, plans and careers. The major factors that may play a key role in determining the care giver burden may be both factors within and outside the family structure such as financial and educational, occupation, marital status and adjustment, culture, social support, pattern of communication, severity level of the illness, age of patient, call for medical support etc. (D Pelchat et al., 1999).

After so many decades, undergoing extensive research work, stigma still remains an issue of debate on how to conceptualize, especially when it comes to mental illness and ID. According to Goffman's (1963) stigma is "undesirable or discrediting attribute that reduces the status of the individual in society". This notion of stigma is debated and argued as it only reflects a limited helpfulness in conceptualizing health associated stigma. Stigma is now regarded as a process, which is shaped by structural and cultural forces. "Thornicroft et al., 2007 argue that stigma research in people with mental disorders (and other health disorders) should focus more on aspects of prejudice and discrimination, a view also held by proponents of the social model of disability."

People with ID and mental illness are time and again found to have the highest degree of social exclusion due to the stigma attached to the notion of ID & mental illness. This population is reported to bear the ill effects of stigma in almost every aspect of their social and personal life such as health, education, community living & housing, employment etc. During the almost last two decades it has been seen that a lot of work on studying and reducing the stigma related to mental illness has been done and documented. But the efforts are still lacking when it comes to ID. (N Ditchman et al., 2013). The current study attempts to study and explore the notion of perceived stress, social support, family burden and stigma faced by the individuals involved in care-giving services of persons with ID

Objective of the study

To assess the perceived stress, social support, family burden and stigma in caregivers of persons with intellectual disability.

To study the relationship between stress, social support, family burden and stigma in caregivers of persons with intellectual disability.

MATERIALS AND METHOD

The present study was a cross-sectional hospital based study conducted at the outpatient department of a tertiary care teaching institute. Sixty family members of children with intellectual disability were purposively interviewed using General Health Questionnaire – 12 (Goldenberg and Williams, 1988), Perceived Stress Scale (Cohen and Williamson 1988), Perceived Social Support Assessment Scale (Zimet et al., 1988), Family Burden Interview Schedule and Family Interview Schedule (stigma items by Sartorius et al., 1996). Caregivers with either sex between 18 to 65 years of age, who had given consent and able to comprehend the instructions were included in the study. Caregivers with chronic physical/mental illness, substance dependence (except nicotine) were excluded.

Children with intellectual disability of either sex between 4-14 years of age fulfilling the ICD-10 (WHO, 1993) criteria for intellectual disability were only considered for the present study. Children with any co-morbid psychiatric or major medical illness or substance dependence (except nicotine) were excluded.

Data collected was entered in the master chart and later analysed using appropriate statistics with the help of Statistical Package for the Social Sciences 16th version (SPSS 16). Descriptive statistics – frequency, percentage, mean, standard deviation, and for association between variables Pearson coefficient of correlation 2-tailed test was used.

RESULTS

Socio-demographic characteristics of care givers

as depicted in table 1 a total number of 60 care-givers (76.7% were Hindu, 16.7% muslim) included in study (N=60), majority of them belonged to rural background and almost equal percentage were living as nuclear families (71.7%) out of which 41 respondents were female (mother of the child with ID) and 19 were male (father) which identified as primary caregiver of the patient. Mean age of care-givers was 33.98. 40% & 35% of the participants were educated upto secondary and primary level respectively. Half of them were unemployed and 40% were engaged in self employment with more than 90% had their income below 10k/month.

Socio-demographic characteristics of patients

Socio-demographic analysis of patients in Table 2, says that mean age was 10.32 years, with 68.3% being male and 31.7% were female. 20% had not been to school, 70% of the patients were educated upto primary level and only 10 % were studied upto secondary level of school education. More than half (56.7%) of the patients were married and 43.3% were single. Largely they were not working (58.3%), only 36.7% were reported to work. Analysis shows that there was strong evidence of family history (61.7%) with mean age of diagnosis was 4.88 years (standard deviation 4.10), avg. duration of treatment was 5.15 years. Clinically, more than 65% of the patients reported to have delayed or impaired developmental milestones like holding neck, sitting, standing, walking and speech.

Table 1: Socio-demographic characteristics of care givers

Variables		Mean \pm SD N (%)
Age in years		33.98 \pm 4.41
Relation	Mother	41(68.3)
	Father	19(31.7)
Education	No Formal Education	9(15.0)
	Primary	21(35.0)
	Secondary	24(40.0)
	Higher Secondary	4(6.7)
	Post Graduate	2(3.3)
Occupation	Employed	6(10.0)
	Self employed	12(40.0)
	Unemployed	30(50.0)
Religion	Hindu	46(76.7)
	Muslim	10 (16.7)
	Other	4(6.6)
Residence	Rural	43(71.7)
	Semi-urban	7(11.7)
	Urban	10 (16.6)
Monthly family income in Rs.	Up to 5000	32(53.3)
	5000-10000	25(41.7)
	Above 10000	3(5.0)
Family type	Nuclear	42(70.0)
	Joint	12(20.0)
	Extended	6(10.0)
No. of family member		1.28 \pm .40
Duration of contact		10.32 \pm 3.78

Perceived Stress

As shown in the table 3 data analysis reveals a level of moderate perceived stress among 83% of the care giver. Nearly 12% of care givers reported to have high levels of perceived stress.

Social Support

As shown in the table 4 assessment and analysis of the scores of perceived social support from different source of support by instrument, findings shows that only 16.7% of the families reported to have high social support from significant others, 45% care-givers have scored upto moderate level and 38.3% have reported to have low social support from significant others. When it comes to family as a source for social support, 61.7% have low level, 21.7% as moderate and only 16.7% have reported to have high level of social support. Social support from friends was found of low levels in 63.3%, moderate in 23.3% and high level social support in only 13.3%. Overall the total social support scores shows that half of the care givers fall into low level and 40% to moderate and only 10% were in high level of support.

Family Burden

As shown in the table 5 family burden was assessed in multiple areas where the data analysis shows that 41.7% had severe, 51.7% had moderate and only 6.7% reported not to have any financial burden. Half of the care givers had reported to

have severe level of burden when it comes to disruption of routine family activities, 33.3% have moderate level and 16.3% reported no burden. 53.3% have severe burden, 40% moderate and 6.7% reported no burden due to disruption of family leisure. 28.3% had severe, 41.7% moderate, 30% reported no burden due to disruption of family interaction. 45% had severe, 26.7% moderate and 28.3% had reported no burden due to effects on physical health of others. 71.1% had severe, 11.7% moderate and 16.7 reported no burden due to effect on mental health of others. 41.7% had severe and 56.7% care givers reported to have a moderate total family burden. Subjective burden was absent in 78.3% and present in 21.7% care-givers.

Table 2: Socio-demographic characteristics of patients

Variables		Mean \pm SD N (%)
Age in years		10.32 \pm 3.78
Sex	Male	41(68.3)
	Female	19(31.7)
Education	No Formal Education	12(20.0)
	Primary	42(70.0)
	Secondary	6(10.0)
Marital status	Single	26(43.3)
	Married	34(56.7)
Occupation	Student	3(5.0)
	Working	22(36.7)
	Nonworking	35(58.3)
Family history	Yes	37(61.7)
	No	23(38.3)
Age of diagnosis in years		4.88 \pm 4.10
Duration of treatment in years		5.15 \pm 3.90
Past hospitalization	Yes	14(23.3)
	No	46(76.7)
Birth Cry	Yes	41(68.3)
	No	19(31.7)
Neck Hold	Yes	37(61.7)
	No	23(38.3)
Sitting	Yes	43(71.7)
	No	17(28.3)
Standing	Yes	44(73.3)
	No	16(26.7)
Walking	Yes	44(73.3)
	No	16(26.7)
Speech	Yes	48(80.0)
	No	12(20.0)

Table 3: Perceived Stress

Stress Level	Frequency	Percent
Low Stress	3	5.0
Moderate Stress	50	83.3
High Perceived Stress	7	11.7
Total	60	100.0

Table 4: Social Support

Source of Support	Level of Support	<i>f</i>	(%)
Significant Other	Low Support	23	38.3
	Moderate Support	27	45.0
	High Support	10	16.7
Family Support	Low Support	37	61.7
	Moderate Support	13	21.7
	High Support	10	16.7
Friends Support	Low Support	38	63.3
	Moderate Support	14	23.3
	High Support	8	13.3
Total Support	Low Support	30	50.0
	Moderate Support	24	40.0
	High Support	6	10.0

Table 5: Family Burden

Family Burden Area	Level of Burden	<i>f</i>	%
Financial burden	No Burden	4	6.7
	Moderate Burden	31	51.7
	Severe Burden	25	41.7
Disruption of Routine Family Activities	No Burden	10	16.7
	Moderate Burden	20	33.3
	Severe Burden	30	50.0
Disruption of Family Leisure	No Burden	4	6.7
	Moderate Burden	24	40.0
	Severe Burden	32	53.3
Disruption of Family Interaction	No Burden	18	30.0
	Moderate Burden	25	41.7
	Severe Burden	17	28.3
Effect on Physical Health of Others	No Burden	17	28.3
	Moderate Burden	16	26.7
	Severe Burden	27	45.0
Effect on Mental Health of Others	No Burden	10	16.7
	Moderate Burden	7	11.7
	Severe Burden	43	71.7
Total Score on Family Burden	No Burden	1	1.7
	Moderate Burden	34	56.7
	Severe Burden	25	41.7
Subjective Burden	Present	13	21.7
	Absent	47	78.3

Table 6: Stigma

Stigma items		%
Neighbors would treat differently	Not at all	48
	Sometime	33
	Often	16
	A lot	3
Spend time worrying	Not at all	53
	Sometime	27
	Often	17
	A lot	03
Need to hide fact	Not at all	55
	Sometime	26
	Often	15
	A lot	4
Helped other people to understand	Not at all	51
	Sometime	37
	Often	10
	A lot	02
Effort to keep as secret	Not at all	54
	Sometime	13
	Often	29
	A lot	04
Worry that neighbors would avoid	Not at all	60
	Sometime	18
	Often	18
	A lot	04
Explaining to others that he/she is not crazy	Not at all	64
	Sometime	25
	Often	11
	A lot	00
Worry that you would be blamed	Not at all	66
	Sometime	19
	Often	14
	A lot	01
Marriage	Not at all	44
	Sometime	24
	Often	28
	A lot	04
Worried about taking him/her	Not at all	58
	Sometime	27
	Often	13
	A lot	02
Ashamed / Embarrassed about it	Not at all	54
	Sometime	26
	Often	16
	A lot	04
Sought out families with a person with epilepsy/mental illness	Not at all	65
	Sometime	27
	Often	07
	A lot	01
Felt grief or depression	Not at all	11
	Sometime	21
	Often	25
	A lot	43
Felt it might be your fault	Not at all	72
	Sometime	21
	Often	07
	A lot	00
Total Score in Stigma Items (Mean \pm SD)		10.14 \pm 6.11

48% care givers informed neighbors wouldn't treat them differently, but 33% agreed to that fact on sometime, 16% found it often. 27% care giver reported that some times they spend time worrying regarding stigma. 15% respondent often and 26% some time, need to hide fact. 10% often and 37% sometimes helped other people to understand regarding disability. 4% reported, a lot to put efforts to keep a secret, 29% often and 13% sometimes. Equal percentage (18%) found to have often and sometimes worry that neighbors would avoid them. 11% often and 25% sometimes, reorted explaining to others that their child is not crazy. Nearly 30% have reported to have stigma related to maarrriage and embarrasment due to disabilit sometimes. 43% of care giver reported to feel depression or grief a lot of time and 23% feel it often. 27% sometimes consider them self as resposible for the disability of the member.

Table 7: Correlation

Variables	Stress	Social Support	Burden	Stigma
Age	-.005	.052	-.023	-.004
Sex	-.041	-.113	-.184	.116
Education	-.095	.031	.168	-.229
Family history	-.077	.212	-.053	
Age of diagnosis	-.143	.168	.162	-.104
Duration of treatment in years	.111	.015	-.276*	.148
Past hospitalization	.045	-.007	-.214	.006
Age	-.143	.168	.162	-.104
Relation	-.110	-.024	.032	.031
Education	-.165	-.201	.058	.124
Occupation	.067	-.037	.023	-.042
Religion	-.121	-.287*	.036	-.162
Residence	-.057	-.104	-.234	-.073
Monthly family income	-.291*	-.285*	.017	-.010
Family type	-.077	.212	-.053	.003
No. of family member	-.154	.014	-.050	.119

As shown in table 7 correlation of stress, social support, burden and stigma with other demographic and clinical variables shows following significant findings: Family Burden is found to have a significant negative correlation with duration of treatment. Social support and percieved stress both are significantly negatively correlated with monthly family income. Rest of the value didn't fall into significant level of correlation.

DISCUSSION

The present study aimed to assess the perceived stress, social support, family burden and stigma in caregivers of persons with intellectual disability and also the correlation of these variables with that of demographic and clinical characteristic of care givers and patients. Results from data analysis of socio-demographic variables shows that the mean age of care givers was below 35 years, which is considered as the most productive

decade of life. Majority of the study participants were from rural background and educated up to secondary level at highest, this may be suggestive of probably they lack the resources and scientific knowledge related to medical and disability services. Clinical and socio-demographic variables of persons with ID shows that mean age was 10.32 years (SD 3.78), 41 male and 19 female (n=60), mean age of diagnosis 4.8 years, mean of duration of treatment 5.5 years, more than 70% have impairment in speech, walking and standing. It clearly shows that all of the patients with ID who participated in study were highly dependent on their care givers for all their basic and higher daily needs. Likewise the findings of the previous similar studies, current study findings clearly highlighted that there is significant perceived stress among the care givers of persons with ID. One can assume the state of mental well being of these care givers involved in delivering the services to their family members. High scores on perceived stress scale, indicates towards poor mental health status of family members (care givers) also making them vulnerable to common mental health issues. Findings of the current study should be taken as an indication for the need of immediate intervention to restore and improve the overall capacity by reducing the stress. It is a well established fact that family functions as a system, consisting of interdependent units. If any of the family members is struggling with a challenge like in case of ID, the whole system gets affected.

Findings of the study highlighted that more than half of the participant care givers experienced a severe degree of family burden in almost all the domains of social, financial and personal aspects of daily life activities. The family burden as assessed by current study shows that a significant disruption of domains like financial burden due to cost of lifelong medical treatment and other related factors is also a key factor, especially to the families of low socio-economic status. The process of care giving to Effect on mental health of others is also another important domain of the family burden, which is found to be severe in more than 70% of the care givers. Physical health is also getting negatively affected as the results shoes that 45% care givers had severe and nearly 27 % reported moderate burden. As per findings of our study, disruption of routine family activities, disruption of family leisure, disruption of family interaction were among other domains of Family Burden which were affected significantly. These findings were backed by previous similar studies (Ampalam et al., 2012, Maheshwari, 2014) which also highlighted that both the parents, i.e. father and mother of ID group were more burdened than their respective counterparts from non-ID group.

One of the previous studies (R de Souza, 2019) attempted to explore the perceived stress and coping strategies of parents of children with ID. 50 parents were assessed in that cross-sectional study and most of the participants were females having more than high school education and were from upper lower class and middle class. When we compare the variable characteristic with that of our study having more male caregivers and also the lower education level comparatively, but results of both the studies shows that higher perceived stress in

caregivers of person with ID. It clearly indicates that the notion of perceived stress is independent of education and socioeconomic status of family. Though it has been advocated by many scholars that low socioeconomic status and lower level of education in parents or care givers act as a vulnerable factor, adding to more complicated care and poor quality of life.

Managing a child with ID requires lifelong continuous efforts from parents. Care givers need to put extra effort and time in fulfilling the needs of persons with ID. It is very difficult to deliver these needs all alone without social support. The role of social support is vital in management of this population. One of the previous studies (D Pandey & P Dubey, 2019) shows that the impact of social support on stress of care givers of persons with ID was significant. Various sources of social support assessed in current study were support from significant others, from friends and family. Findings shows that more than half of the care givers reported to have a low social support, making it even more difficult for them to manage their wards in absence of support. Stigma was also one of the important variables studied in current study. One of the earlier study (D Tilahun et al., 2016) done with a sample size of 102 care givers of person with ID found that most of the care givers reported stigma experience on different aspects such as indifferent treatment by others, feeling of shame about their wards condition, hiding the facts and keeping secrets. The results also show that stigma was independent of gender, age, and the diagnosis and education level of care giver. In our findings we also found that majority of the care givers reported to experience stigma irrespective of the clinical and demographic variables of patients and care givers.

Limitations of the study: Like all studies, the current study also has certain limitations and boudaries. The present study was a cross sectional study in nature hence no folloup was made and the degree of severity of percived stress, social stigma and family burden could not be generalised. The sample size was small and it was reflected that most of the particiapnt were from rural background and lower socio economic status having low educaiton level, all these factors making sample a homogenous group. It would be better to have a hetrogenous group to study. Samples were not selected randomly was also a limitation of the study.

CONCLUSION

The findings of the current study goes with the most common hypothesis that care givers of the persons with ID are one of the most excluded group, when it comes to social integrity and community living. Their perceived stress is high, stigma and family burden adds to already existing challenges. Lack of social support from family and friends is major concern. The mental and physical health of care givers is at stake and so thus the care and needs of their wards. Despite of growing efforts from different sectors of both public and private domains, these needs and variables needs to be addressed immediately by stakeholders. More programmes and policies should come up that involve this perspective of care givers. Living with a child having ID is very stressful and involve a lot of burden. The burden, social stigma, stress and social support is independent of the gender, education level of parents and diagnosis. The findings of the study stressed on the fact that interventions should focus more on education and awareness to target stigma and support needs of care gives so as to reduce their stress.

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