

Challenges Faced by Caretakers of Intellectually Disabled Children

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Abstract

This study explores challenges faced by caregivers of intellectually disabled children. The study was conducted with a sample of 25 people (caretakers of intellectually disabled children) (N=25) both males and females from Fortis Hospital, New Delhi, and Global Institute of Medical Science, Bangalore, Udaan (NGO), New Delhi and Samarthanam (NGO) Bangalore. A five-point rating scale was used to collect data from caretakers with 5 domains: Social Stigma, Financial Concerns, Future Concerns, Happiness Quotient, and General Stress. The result of the study shows that there is a positive correlation between age and general stress level, between family income and general stress, and family income and happiness quotient. The study also reveals that there exists a mean rank difference in general stress among different occupations. It proved that the home employed population was having the least stress compared to other occupations, also there is a negative correlation between happiness quotient and social stigma.

INTRODUCTION

An intellectually-disabled child in a family is usually a serious concern for the parents. It often requires reorientation and re-evaluation of family goals, responsibilities and relationships. In India, the majority of persons with mental retardation

have traditionally been cared for by their families. This home-based care has resulted in many consequences. Factors, such as changes in the social system (e.g., breaking up of joint families) and the economic system (e.g., unemployment, inflation, etc.) have contributed to the stress that

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parents of mentally retarded children experience. Living with such children can be stressful for caregivers in the family. This paper explores the psychological and emotional, social and economic challenges that parents or guardians experience in caring the mentally ill children.

HEALTH AND MENTAL HEALTH

World Health Organization (WHO) defines human health in a broader sense in its 1948 constitution as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. (WHO, 1948). Mental health includes “subjective well-being, perceived self-efficacy, autonomy, competence, inter-generational dependence, and self-actualisation of one’s intellectual and emotional potential, among others. WHO further states that the well-being of an individual is encompassed in the realisation of their abilities, coping with normal stresses of life, productive work, and contribution to their community (World Health Report, 2001).

TYPES OF MENTAL ILLNESS

Depression, generalised anxiety disorder, panic disorder, obsessive-compulsive disorder, post-traumatic stress disorder, social anxiety disorder, specific phobias are some common types of mental illness. Signs and symptoms of these include feeling sad, difficulty to concentrate, excessive fears or worries, extreme mood swings,

withdrawal from activities previously enjoyed, tiredness, detachment from reality (delusions), paranoia or hallucinations, alcohol or drug use, changes in eating habits, changes in sex drive, immense anger, suicidal thoughts, etc.

The American Association on Mental Retardation defines mental retardation as “subaverage general intellectual functioning which originates in the developmental period and is associated with impairment in adaptive behaviour” (Reschly et al., 2002). It is generally considered that 2 per cent of the Indian population constitutes persons with mental retardation and the prevalence of mental retardation varies from 0.22 per cent – 32.7 per cent per thousand population (Thiyam et al., 2008). Relatives of intellectually disabled children report a wide range of reactions to their situations in dealing with such children.

MENTAL HEALTH POLICY

India is revising its mental health legislation with the Indian Mental Healthcare Act 2017 (IMHA). When implemented, this legislation will apply to over 1.25 billion people. In 2005, the World Health Organization (WHO) published a resource book (WHO-RB) on mental health, human rights, and legislation, including a checklist of 175 specific items to be addressed in mental health legislation or policy in individual countries. Even following the publication of the United Nations Convention on the Rights

of Persons with Disabilities (CRPD) 2006, the WHO-RB remains the most comprehensive checklist for mental health legislation available, rooted in UN and WHO documents, and providing the most systematic, detailed framework for human rights analysis of mental health legislation.

MENTAL DISABILITY TO INTELLECTUAL DISABILITY (ID)

The term “intellectual disability” is gradually replacing the term ‘mental retardation’ nationwide. Advocates for individuals with intellectual disability have rightfully asserted that the term “mental retardation” has negative connotations, has become offensive to many people, and often results in misunderstandings about the nature of the disorder and those who have it. (Salvador-Carulla and Bertelli, 2008).

CARETAKER

A caretaker is someone who is responsible for looking after another person, for example, a person who has a disability or is ill or very young. Typical duties of a caregiver might include taking care of someone who has a chronic illness or disease; managing medications or talking to doctors and nurses on someone’s behalf; helping to bathe or dress someone who is frail or disabled; or taking care of household chores, meals, or bills for someone who cannot do these things alone. (Schulz, R., Eden, J., and National Academies of Sciences, Engineering, and Medicine, 2016).

TYPES OF CHALLENGES FOR THE CAREGIVERS OF AN ID CHILD

In Education

Education, particularly school education, is the domain, which warrants much serious attention for ID children in school. UNESCO and Tata Institute of Social Science report States of the Education Report for India 2019: Children with Disabilities record 75 per cent of five-year-olds with disabilities and a quarter (more than one in four) of children with disabilities (in the age group of 5 to 19 years) do not attend any educational institution. (UNESCO, 2019). The position paper of the national focus group on education of children with special needs brought out by NCERT in the year 2006 (NCERT, 2006) as part of the curriculum revision, which resulted in the National Curriculum Framework 2005 (NCERT, 2005) recommends that the professional development of teachers and educators is an important issue and must incorporate attitudinal change, and the knowledge and skills necessary to lead to an inclusive society.

Economic Challenges

The daily lives and activities of parents are very much affected by the presence of a intellectually disabled child. Much time was spent looking after the child and as a result, they were not able to do other important activities such as business. Income generation in the family was affected and this further

escalated family poverty as explained by a mother of a child with a seizure disorder and mental retardation (Ambikile and Outwater, 2012).

Social Challenges

Social services, stigma and caring responsibilities were areas, which posed major concerns for parents. Other important issues included a lack of public awareness, social support, and social life. As Ambikile and Outwater observed that inadequate social services for children with mental disorders were the most challenging issue for parents. They were concerned about education of the child and to a lesser degree hospital care. The most distressing aspect was the inability of the child to acquire education due to an inadequate number of schools. Parents spent a lot of time looking for schools that could accommodate the child (Ambikile and Outwater, 2012).

Challenges Experienced by Caretakers of Intellectually Disabled Children

Taking care of a child with intellectual disability can have both positive and negative effects on parents. The goal of all caring parents is to provide the best quality of life for their children as well as to maximise their potential. Each family's situation and coping ability is different based on the type and severity of disability of their child as well as other factors including their socioeconomic status, education, culture, support network, and individual personality and parenting style. Inevitably, the

family functions differently, in ways that can be perceived both positively and negatively. There is no doubt the circumstances significantly impact the quality of life of the child and the parents in this situation. Most of the studies on the impact of caregiving have revolved around the stress and depression that the parents encounter.

REVIEW OF RELATED LITERATURE

Mental health and intellectual development are the interest areas of many researchers for long. Some of those are mentioned here:

A study on stress and anxiety in parents of mentally retarded children was conducted by Majumdar, Pereir and Fernandes (2005) at Child Guidance Clinic of tertiary care psychiatry hospital Goa. The study found that the parents in group A had significantly higher frequency of stressors and level of anxiety as compared to those in group B and C. A positive correlation was found between the level of stressors and anxiety (Majumdar, Pereira, and Fernandes, 2005).

A research to determine the burden of mental illness in the family/caregiver and the community was conducted by Nyati and Sebit (2002) with rehabilitation centers, community day centers, resettlement villages and in the community in three provinces — Harare, Bulawayo and Masvingo, in Zimbabwe was done. The study concluded that the caregivers were mainly women and unemployed, whereas patients

were mostly male. Caregivers faced multiple problems, but they were more tolerant to patients' behavior than the community at large.

A study on the challenges of caring for children with mental disorders was conducted by Semel Ambikile and Outwater (2012). The study revealed psychological and emotional, social and economic challenges caregivers endure while living with mentally ill children (Ambikile & Outwater, 2012).

Another study on parenting stress among mothers of children was by Feizi, Najmi, Salesi, Chorami and Hoveidafar (2012) on mothers of 6–12 years old children with chronic physical disease, psychological disorder, sensory motor and mental problems found that mothers of children with sensory-motor mental and chronic physical problems experience more stress than mothers of children with psychological disorders. The stress score of mothers of children with psychological disorders was lower than the other two groups. Also there was a significant difference between the score of mothers of children with chronic physical problems and mothers of children with psychological disorders regarding parent-child dysfunctional interaction (Feizi, Najmi, Salesi, Chorami, and Hoveidafar, 2014).

An interesting study on parental stress and autism: are there useful coping strategies?, conducted by Mancil et al., (2009) has described about various coping strategies used by parents of children with Autism

Spectrum Disorders(ASD). The study shows that coping strategies parents of children with ASD used to deal with stressors and discuss implications for researchers and practitioners working with children with ASD and their families who exhibit increased levels of stress

The reviews above indicate that as the level of retardation in children increases, the stress level of parents also increases and the community behaviour is a greater concern rather than a child with intellectual disability for such parents. The studies reveal that the prime concern of the parents of intellectually disabled children is related to their child's future, and also suggested certain important coping strategies to overcome stress related to caring of such child.

Following are the Operational Definitions of the Terms Used in the Research

Caretakers

In this study, both mother and father of the child will be considered as caretakers.

Challenges

Difficulties faced by the care takers while bringing up their disabled child.

Mentally disabled

Person with anxiety disorders, attention deficit disorder, autism spectrum disorder, eating disorder, mood disorder, schizophrenia or other any mental disability.

Intellectual disability

Disability characterised by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills (Milani, D., Ronzoni, L., & Esposito, S., 2015).

OBJECTIVES OF THE STUDY

- To understand the attitude of the parents towards mental disability of their child.
- To study the happiness quotient of parent in relation to their disabled child.
- To learn about the behaviour of society toward these child.
- To find out the concerns of parents of such children regarding their child's future.

Following Hypothesis Were Formed for the Objectives

- There is a correlation between age and general stress.
- There exist a correlation between general stress and family income.
- There is no correlation between family income and happiness quotient.
- There is a significant mean rank difference in general stress among different occupation.
- There is significant mean difference between all the categories of occupation in terms of financial trauma.

- There is no significant mean difference between male and female in terms of social stigmas.
- There is a correlation between family income and future concern.
- There is a negative correlation between social stigma and happiness quotient.

The researcher wanted to study the attitude and concerns of caretakers of mentally disabled children living in urban cities (Delhi and Bangalore). The population of Bangalore is around 8 million and Delhi is around 20 million and around 3 per cent approx of any population is mentally disabled, so the study will have some meaningful consequence for around 5 lakhs caretakers within the two cities. This research will help the researcher to understand the concerns of caretakers of children with mental disability and help them to overcome these issues by an in-depth study on this topic.

SAMPLE AND TOOL

An informed consent form was given to the heads of the participating institutes. Parents of intellectually disabled children were informed about the research. To obtain the desired result, researchers used a questionnaire based on the domains of the objectives.

A self-prepared questionnaire was used to understand the challenges of caretakers, it includes information

about the age, gender and name of the participating parent. It is divided into four sections: social stigma, which contains six questions and explains the difficulties society places on these parents and children; financial challenges in their daily lives, which contain five questions; future concerns, which contain five questions; stress in their daily lives, which contains eight questions; and other general stress, which contains two questions. The tool consists 26 questions with the following options — never rarely sometimes often always. Data was analysed using SPSS tool. The confidentiality of each and every participant was maintained, in case of any issue regarding the emotional behavior aspects of the participants while collecting data was treated

with proper measures and not within sensitivity.

DISCUSSION

The study attempted to test the 8 hypothesis on the challenges faced by caretakers of intellectually disabled children. This section discusses the findings of the statistical analysis, namely correlation, mean rank difference, independent sample tests and anova. So the hypothesis formulated were: with the help of spearman’s correlation test, it was found that there is a positive correlation between age and general stress. The strength of association between the 2 variables is low considering the “r” value 0.231. All the assumptions for conducting the test were met. Hence, null hypothesis accepted.

Table 1: Correlation between age of the caretakers and the general stress

			Age	GS total
Spearman’s rho	Age	Correlation Coefficient	1.000	.231
		Sig. (2-tailed)	.	.107
		N	50	50
	GS total	Correlation Coefficient	.231	1.000
		Sig. (2-tailed)	.107	.
		N	50	50

Spearman’s correlation 11

Spearman’s correlation was conducted; there was a positive correlation between family income and general stress. The strength of

the association is low between the 2 variables considering the “r” value 0.199. All assumptions for conducting the test were met. Therefore, null hypothesis accepted.

Table 2: Correlation between family income and general stress

			Family income	GS_total
Spearman's rho	Family income	Correlation Coefficient	1.000	.199
		Sig. (2-tailed)	.	.166
		N	50	50
	GS_total	Correlation Coefficient	.199	1.000
		Sig. (2-tailed)	.166	.
		N	50	50

Spearman's correlation 21

Spearman's correlation test was conducted after which we concluded that there is a positive correlation between family income and happiness quotient. Hence, alternate hypothesis accepted.

Table 3: There is a correlation between family income and happiness quotient

			Family income	HQ total
Spearman's rho	Family income	Correlation Coefficient	1.000	.066
		Sig. (2-tailed)	.	.649
		N	50	50
	HQ total	Correlation Coefficient	.066	1.000
		Sig. (2-tailed)	.649	.
		N	50	50

Spearman's correlation 31

After conducting Kruskal Wallis mean rank test, sample population of business category had more stress compared to the other three categories. Whereas, home employed population was having the least stress. Hence, null hypothesis accepted.

Table 4: Mean rank difference in general stress and different occupations

Ranks			
	Occupation	N	Mean Rank
GS total	Business	14	27.57
	Govt. service	20	25.78
	Private service	11	24.14
	Home employed	5	21.60
	Total	50	

Kruskall Wallis 11

After conducting one-way anova, we found out that there exist no mean difference between the groups in terms of financial trauma as the p value is 0.447, which is greater than 0.05. So, the alternate hypothesis is accepted.

Test of homogeneity of variances

Table 5: Finance total

Leven statistic	df1	df2	Sig.
.977	3	46	.412

Table 6: Mean difference between male and female in terms of social stigmas

	Sum of Squares	df	Mean Square	F	Sig.
Between groups	29.560	3	9.853	.903	.447
Within groups	502.060	46	10.914		
Total	531.620	49			

Anova 11

After conducting t-test, we found out there is no significant mean difference because the value is less than 0.05. So, null hypothesis accepted.

Table 7: Independent samples test

F		Levene's Test for Equality of Variances		t-test for equality of means					
		Sig.	t	df	Sig. (2- tailed)	Mean difference	Std. error difference	95% Confidence interval of the difference	
								Lower	Upper
ss total	Equal variances assumed	3.204	.080	-1.753	48	.086	-2.13194	1.21614	-4.57715
	Equal variances not assumed			-1.859	41.747	.070	-2.13194	1.14660	-4.44629

t-test 1

We conducted spearman’s correlation test, according to the result, there is positive correlation between both the variables, but the strength of association is low.

Table 8: Correlations

		Future total	Family income
Future total	Pearson correlation	1	.285*
	Sig. (2-tailed)		.045
	N	50	50
Family income	Pearson correlation	.285*	1
	Sig. (2-tailed)	.045	
	N	50	50

* Correlation is significant at the 0.05 level (2-tailed).

There is a negative correlation between social stigma and happiness quotient.

After conducting the spearman’s test, we concluded that there exist negative correlations between social stigma and happiness quotient with a value -.200. Hence, null hypothesis accepted.

Table 9: Correlations

			HQ total	SS total
Spearman’s rho	HQ total	Correlation coefficient	1.000	-.200
		Sig. (2-tailed)	.	.163

		N	50	50
SS total	Correlation coefficient		-.200	1.000
	Sig. (2-tailed)		.163	.
	N		50	50

Thus, the analysis in the study present the challenges faced by caretakers of intellectually disabled children.

FINDINGS AND CONCLUSION

Caring a child with intellectual disability can be highly stressful in terms of social stigmas, financial aspects, health aspects and many other aspects as well. The study reveals that age of the parents and general stress have a positive correlation, which shows that with age stress of the parents also increases. There is a positive correlation between family income and general stress as well, which means, family income effects the stress level among the parents.

Result also shows that people with different occupations had different stress level. People who had their own business were the most stressed; population working in the government and private sector had lesser stress level, and home employed population have the least level of stress.

The study further shows there is no mean difference in financial stress level with respect to different occupations. This means that population having their own business, people working

in government and private sectors, and own employed population were equally stressed in terms of financial concerns. There exist no mean difference among male and female in terms of social stigma, which means both are equally stigmatised.

There is a positive correlation between family income and future concerns, as the income increases, stress related to future also increases. Increase in social stigma leads to decrease in the level of happiness among the parents, the study proves that there is a negative correlation between happiness quotient and social stigma.

The research conducted is mainly focused on the challenges faced by caretakers of intellectually disabled (ID) children in terms of social stigma, financial concerns, future concerns and stress in general. In a country like India, care provided to differently abled (DA) people is mostly home based, family is the major support for DA, so stress and traumas are inevitable among these families.

Birth of an ID child in the family is one of the most traumatic events for parents as well as family. The primary purpose of our study was to understand general stress among the parents of intellectually disabled children with respect to their age. As per previous research, the stress level increases with the age (Lefley, 1987). Our results revealed that there is a positive correlation between age of the parents of disabled children and

general stress level. So as the age of the parents increases, the stress level also increases.

Family income is one of the major concerns for these parents; earlier research suggests that stress of these parents is also affected by their family income (Sen and Yurtsever, 2007). The current study also concludes that there is a positive correlation between family income and the stress level. Stress level decreases with increase in income.

The study also informs that there is a significant mean rank difference in general stress among different stress level, population having business has highest stress level, whereas home employed people have the lowest, and also there was not much of financial stress with respect to occupation. There is no significant mean difference between mother and father in terms of social stigma. The result is clearly contradicting previous study (Gray, 1993), according to which there is a strong tendency for mothers to feel more stigmatised as compared to the fathers. This study also confirms the findings of some of the previous research studies which found that as social stigma increases, stress level also increases in many areas, such as relationships, jobs, etc. (Wahl and Harman, 1989).

This study has its limitations in terms of sample size and other variables. More samples could have been included in the study along with more number of NGOs, hospitals,

doctors and psychologists working with intellectually disabled children to increase the richness of the study. It is suggested that research on health concerns of the caretakers could be undertaken for a deeper understanding of the status of mental and physical strength of caretakers of such children. This would also help in assessing coping strategies for these concerns.

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