KAP STUDY

DEPRESSION AMONGST PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITY

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ABSTRACT

Background: Parental stress is the major factor that increases a risk of unwillingly placing children with disabilities. The aim of our study is to assess the frequency of depression amongst parents of children with intellectual disability.

Methods: This was a cross sectional study conducted for 10 months in various hospitals and rehabilitation centers in Karachi, Pakistan. Participants were inducted using purposive sampling technique. Parents of intellectually challenged children up to 18 years of age were included and a self-administered questionnaire was utilized for data collection both in English and Urdu. PHQ 8 was used to assess the severity of depression amongst parents. For all purposes, p-value of <0.05 was considered statistically significant. Permission was sought from the ethical review board.

Results: High proportion of parents interviewed suffered significantly from moderate to severe depression [223 (66.2%)]. Gender comparison revealed [186 (75.9%)] females had moderate to severe depression compared to [136 (40.3%)] males (p-value=0.000). Some factors associated with the child such as severity of disability also had an impact [197 (69.3%)], parents having children with Cerebral Palsy suffered moderate to severe depression as opposed to [26 (49%)] parents of children with Down's Syndrome (p-value=0.03). The most common way to relieve stress was praying practiced by [176 (52.2%)] the parents.

Conclusion: Amongst the parents of children with intellectual disability (ID), a significantly high proportion was suffering from depression. From the child's aspect, age and severity of disability had an impact. Most common strategy identified to overcome depression was praying.

Keywords: Intellectual Disability; Depression; Cerebral Palsy; Down Syndrome.

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INTRODUCTION

Intellectual disability (ID) is characterized by impairments of general mental abilities that impact intellectual functioning such as learning and reasoning and adaptive functioning including communication and independent living. This disability originates before the age of 18 and affects around 1-3% of the world's population.[1,2] Pakistan has one of the highest rates of childhood ID in the world. Prevalence estimates range from 19.1/1000 for serious ID to 65/1000 for mild ID.[3] The lack of opportunities for schooling and employment, along with other economic, cultural and social factors leads to higher levels of stress amongst parents of children with ID. Care giving responsibility of parents takes an entirely different importance when a child experiences functional constraints and possible long-term dependence.[4] Studies have shown an association between parental distress and caretaking of children with developmental cognitive delays.[5] Depressive disorders have become a global concern and are predicted to become the most common reason for disability in low and middle income countries by the year 2020[2]. They are particularly prevalent in developing countries where 10-44% people suffer from depression and anxiety[2].

Studies have proved that child behavioral problem is the single most important characteristic that predicts the psychological state of the caregiver[6].

A research stated that 47% of primary caregivers of ID children were psychologically distressed[2]. Factors such as difficult behavior of the child along with a reserved personal life, child's delay in communication and low socioeconomic class are associated with greater symptoms of depression, anxiety and despair among parents[7]. A study conducted in Pakistan, concluded that the prevalence of depression and anxiety was greater in mothers of children with ID[8].

Despite the high prevalence of childhood ID and increasing frequency of depression in Pakistan, not much work has been done to establish the association[9]. Keeping the prevalence of childhood ID and its suggested association with depression in mind; we intend to assess the frequency of depression amongst parents of children with Intellectual disability.

METHODS

This was a cross-sectional study conducted from July 2015 to May 2016. Target population were parents of all the children who are diagnosed with either Cerebral Palsy (CP) (n=284) or Down's syndrome (DS) (n=53). The sample size when calculated was n=330 based on a prevalence of 8.4% ID (3) with a bound of error of 3% and confidence level of 95% by using the standard formula for calculating sample size for cross sectional study with a categorical outcome.

Sample was selected using purposive sampling technique including parents of Intellectually Challenged (IC) children up to 18 years of age. Parents who have admitted their IC children into special facilities were also inducted in the study. However, parents of children with co-morbid conditions and those who refused to give consent were excluded from the study. Data was collected through personal interview and was developed in English and translated in Urdu language. The questionnaires were originally developed through literature review by the researchers and modified in order to apply to individuals with all levels of education. Personal Health Questionnaire (PHQ-8)[10] was the standard depression scale used to assess the severity of depression amongst the parents. The individuals were given a brief overview of the contents of the questionnaire before being delivered and consent was obtained. After getting written informed consent, the parents were recruited from three health centers in Pakistan.

During the course of study various rehabilitation institutions were also approached for data collection. Data was entered and analyzed using IBM SPSS Statistics version 20. Before analysis, data was cleaned for possible data entry errors. Frequencies and percentages were worked out for categorical variables. Pearson Chi Square test were used to evaluate associations between various qualitative variables of interest. For all purposes, a p-value of <0.05 was considered statistically significant.

RESULTS

The ages of parents in a sample of n=337 were distributed with mean 33.41 ± 8.47.Both mothers (n=245) and fathers (n=92) were enrolled in the study. Moreover, there was a significant association between the disability of the child and depressed state of the parents, n=197 (69.3%) parents having children with CP suffered moderate to severe depression as opposed to n=26 (49%) parents of children with DS (p-value=0.03).

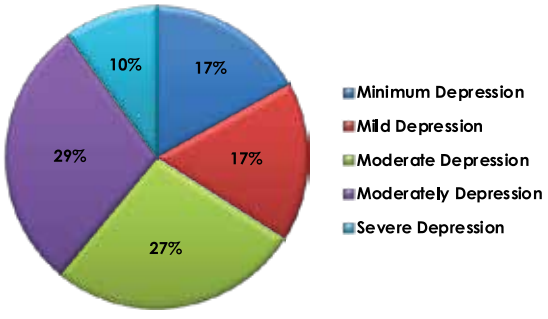

Figure 1: Frequency of Depression in Parents of Intellectually Disabled Children.

An effort was made to identify education status as an important risk factor, n=141 (41.8%) of the sample was uneducated, n=144 (42.7%) had completed basic education which is defined by Matric/Intermediate in Pakistan or its equivalent abroad and n=52 (15.4%) of the parents had received some form of professional education. A significant association was found between education status of the parents and degree of depression. Amongst the uneducated parents n=112 (79.4%) suffered from moderate to severe depression as compared to n=88 (61.1%) in people who have received basic education and n=15 (42.9%) and n=8 (47.1%) in people who had received a Bachelors or Masters degree respectively (p-value=0.001).

Furthermore, monthly family income was used as a measure to deduce the socioeconomic status and study included n=228 (67.7%) people who had a monthly income of less than Rs. 20,000, n=76 (22.6%) between Rs. 20,000 to Rs. 50,000 and n=33 (9.8%) people were earning more than Rs. 50,000 a month. A significant association was seen as n=166 (72.8%) of those belonging to the low socioeconomic class showed moderate to severe depression compared to considerably lower levels seen in those belonging to the upper and middle class (p-value=0.0001).

To assess the number of children and the degree of depression associated with it, sample was subdivided into three categories, where n=162 (48.1%) had up to two children, n=113 (33.5%) had three to four

children and n=62 (18.5%) had more than 5 children. A significant association was established as n=53 (85.5%) of the parents with more than 5 children were suffering from moderate to severe depression as opposed to n=72 (63.7%) amongst those having 3-4 children and 60.5% in those having up to two children (p-value=0.018). In the inducted sample, n=327 (97%) of the people were married, n=5 (1.5%) were divorced and n=5 (1.5%) widowed. A significant association was shown as only n=214 (65.5%) of those married were suffering from moderate to severe depression however, n=5 (100%) of those divorced and n=4 (80%) of those widowed showed the same extent of depression.

Parental ages were distributed over a wide range with minimum age 20 and maximum 60. Age groups were created to test an association with depression. N=155 (46%) were less than 30 years old, n=154 (45.7%) were between 31-45 and n=28 (8.3%) were between 46-60 years of age. Severity of depression was more pronounced towards both ends of the age spectrum of the sample population. As n=104 (67.1%) of the population below the age of 30 showed moderate to severe depression, n=99 (71.5%) of those between 46-60 years of age as opposed to n=53 (64.3%) of the parents who were 30-45 years of age. Furthermore, n=133 (68.2%) of the people living in joint family systems showed moderate to severe depression as compared to n=90(63.5%) living in nuclear families (Table 1 and Figure 1).

Table 1: Risk factors and their association with depression.

RISK FACTORS AND THEIR ASSOCIATION WITH DEPRESSION												
DEPRESSION SCALE												
Risk Factors for Depression		**Minimal**		**Mild**		**Moderate**		**Moderately Serve**		**Serve**		**p-Value**
Diagnosis		n	%	n	%	n	%	n	%	n	%	
	Cerebral Palsy	38	13.1	49	17.3	83	29.2	83	29.2	31	10.9	0.3
	Down Syndrome	18	34	9	17	7	13.2	15	28.3	4	7.5	
Gender of Respondent	Male	33	35.9	22	23.9	24	26.1	10	10.9	3	3.3	0.000
	Female	23	9.4	36	14.7	66	26.9	88	35.9	32	13.1	
	Married	56	17.1	57	17.4	88	26.9	95	29.1	31	9.5	
Marital Status	Divorced	0	0	0	0	1	20	1	20	3	60	0.047
	Widowed	0	0	1	20	1	20	2	40	1	20	
	No	10	7.1	19	13.5	47	33.3	50	35.5	15	10.6	
Education	Matric/O Level	24	16.7	32	22.2	36	25	35	24.3	17	11.8	0.001
	Bachelors	14	40	6	17.1	5	14.3	9	25.7	1	2.9	
	Masters	8	47.1	1	5.9	2	11.8	4	23.5	2	11.8	
Family Income	<20000	27	11.8	35	15.4	70	30.7	70	30.7	26	11.4	0.0001
	20000 - 50000	14	18.4	19	25	16	21.1	22	28.9	5	6.6	
	50000 - 100000	27	36.8	2	10.5	3	15.8	3	15.8	4	21.1	
	>100000	8	57.1	2	14.3	1	7.1	3	21.4	0	0	
Number of Children	2	35	21.6	29	17.9	38	23.5	40	24.7	20	12.3	0.018
	3 - 4	18	15.9	23	20.4	32	28.3	31	27.4	9	8	
	>5	3	4.8	6	9.7	20	32.3	27	43.5	6	9.7	
Age Groups	Less than 30	24	15.5	27	17.4	37	23.9	46	29.7	21	13.5	0.174
	31 - 45	26	16.9	29	18.8	48	31.2	42	27.3	9	5.8	
	46 - 60	6	21.4	2	7.1	5	17.9	10	35.7	5	17.9	

When attitude of doctors with respect to Intellectually Challenged children was ascertained it was observed that an early diagnosis was not seen in majority of the children. This was either due to deliveries occuring at home or diagnosis being missed by the doctors within hospitals. Majority parents

n=200 (59.3%) were satisfied from their first visit to the doctor after their child's diagnosis. However, unfortunately n=136 (40.4%) of the parents were not satisfied. The primary reason seemed to be the doctor not giving them enough time to answer their queries and reassure them.

When most common problems faced by parents who have intellectually challenged children were listed, child's behavior was found to be the most difficult aspect, n=190 (56.4%), as opposed to lack of social interaction, n=29 (8.6%) and lack of opportunities n=21 (6.2%). Moreover, n=97 (28.8%) of the parents listed other causes as the most challenging aspect. These causes mainly included physical dependence n=36 (10.8%), feeding problems n=23 (6.9%) and communication problems n=9 (2.7%). Other miscellaneous causes included frequent infections, sleeping problems and toilet training issues. A significant association was found between the above listed difficulties and depression amongst the parents. From the sample, moderate to severe depression was seen amongst n=130 (68.4%) parents listing child's behavior as the biggest challenge as opposed to n=19 (65.4%) who stated lack of social interaction and n=6 (28.5%) of those who were worried about lack of opportunities. It was also revealed that there was n=68 (70.1%) moderate to severe depression present amongst parents facing other difficulties, majorly being physical dependence, feeding problems, communication problems and financial issues (p-value=0.045) (Table 2).

Table 2: Attitude of the society and association with depression.

ATTITUDE OF THE SOCIETY AND ASSOCIATION WITH DEPRESSION											
DEPRESSION SCALE											
Society's Reactions		**Minimal**		**Mild**		**Moderate**		**Moderately Serve**		**Serve**	**p-Value**
Encouraging and cooperative		n	%	n	%	n	%	n	%	n	%	0.000
	Yes	52	22.4	44	19.0	59	25.4	62	26.7	15	6.5	
Advised to get the right therapies	No	4	4.0	12	12.1	29	29.3	34	34.3	20	20.2	0.004
	Yes	43	21.5	41	20.5	51	25.5	52	26.0	13	6.5	
Were discouraging and asked you not to disclose it	No	13	9.9	15	11.5	37	28.2	44	33.6	22	16.8	0.082
	Yes	4	10.5	5	13.2	6	15.8	14	36.8	9	23.7	
	No	52	17.7	51	17.4	82	28.0	82	28.0	26	8.9	

Table 3 shows that people use several ways to get relief from parental stress. According to the sample, majority of the people prayed to relieve stress n=176 (52.2%). Other strategies used included: talking to a close one about their problems n=34 (10.1%), n=22 (6.5%) going out somewhere, sleeping n=9 (2.7%) and exercising n=5 (1.5%). A significant association was found between the severity of depression and the strategies employed to relieve stress. It was revealed that parents who exercised were least depressed n=1 (20%) moderate to severe depression and people who slept to relieve their stress were most depressed n=8 (88.9%) as compared to other strategies used (p-value=0.017).

Table 3: Strategies to relive parental stress.

STRATEGIES TO RELIVE PARENTAL STRESS											
DEPRESSION SCALE											
Strategies	**Minimal**		**Mild**		**Moderate**		**Moderately Serve**		**Serve**		**p-Value**
Pray	n	%	n	%	n	%	n	%	n	%	0.017
Talk to someone	27	15.3	22	12.5	46	26.1	59	33.5	22	12.5	
about it	4	11.8	7	20.6	12	35.3	6	17.6	5	14.7	
Go out somewhere	4	18.2	5	22.7	6	27.3	4	18.2	3	13.6	
Spend time with family	5	22.7	4	18.2	7	31.8	6	27.3	0	0.0	
Sleep	0	0.0	1	11.1	1	11.1	5	55.6	2	22.2	
Exercise	4	80.0	0	0.0	0	0.0	1	20.0	0	0.0	

DISCUSSION

The birth of an intellectually disabled child in a family opens them up to an avenue of various challenges that can include increased responsibility, altered attention and decreased social interaction which particularly affects the caregivers[8]. The main challenge for these parents is to manage the added responsibility of this child with all the other demands of everyday life[11]. Therefore, these parents are at risk of developing several problems in their family lives including emotional disturbances[12].

Our study revealed that 66.2% of the parents suffered from moderate to severe depression. Previous studies in other countries have shown similar results, two-thirds of parents in Australia, 44.7% in Turkey and 79% in Kenya showed clinical depression[13,14]. Similarly,a study by Gupta and Kaur reported about India and Bangladesh, which also showed higher levels of mental stress in parents of children with intellectual disabilities[15]. However,according to our study, the depression was more severe in females than as compared to males, which was similar to findings in other studies[16]. Mothers are also most influenced by the problems in daily activities of the children while fathers were more affected by low social acceptability of this child.[17] A father's participation and support can therefore lighten the burden on the mother[18].

Contrary to a previous study that stated married parents had a greater degree of depression our study revealed that divorced or widowed parents seemed to be more depressed[19]. Moreover, various other studies also revealed that higher levels of marital quality were related to lower levels of depression and increased parenting efficacy. If the family cannot afford the treatment and rehabilitation costs it adds to their stress levels[20]. Majority of the people in our study said they found out through a doctor, which makes the doctor's role of prime importance. An early diagnosis, was not seen in majority of the children. This was usually seen in the rural settings; either due to deliveries occuring at home or diagnosis being missed by the doctors within hospitals[3]. Majority of the parents were satisfied from their first visit to the doctor after their child's diagnosis, however, unfortunately a large percentage of the parents were not. The primary reason identified was that the doctor did not give them enough time to answer their queries and reassure them.

Parents mentioned that their child's disability came across as a shock to them and understandably they had a lot of questions related to the future prospects Since they are emotionally vulnerable and very stressed at this point, doctor's behaviour provides the scaffolding for the mental framework of these parents and hence plays a key role in the process[3].

Moreover, the doctor is responsible for establishing the mental framework of parents but the society plays an important role in shaping it. In Pakistani culture, where disability of any kind is considered a burden it becomes very difficult for the family to bring up a child who is either sympathised with or rejected.[20] Our study showed that the parents who had cooperative relatives and friends who encoouraged the right treatment and therapies for their child were less depressed as compared to those who were not. Therefore, this can serve as a very important area for intervention when it comes to improving the quality of life for such parents. Despite the recent increase in awareness, spirituality and religiosity being central to perceptions still makes society portray intellectual disability as a parental negligence or punishment[21].

The acceptance of such children in the society is on an increasing trend, n=216 (42.4%) of the parents received a positive reaction from the society, towards their child. Unfortunately, n=116 (34.3%) of the parents in our sample claimed that they were not only isolated by society but were also labeled and discredited. Some even added that they were held responsible for their child's condition. However, they did agree that before their own child was affected, they also viewed having a child with ID as a tragedy or punishment[22].

Parental education also serves as an important indicator of their mentality and ability to cope with whatever comes their way. Those with little or no education usually tend to isolate themselves or their child and do not opt for the proper therapies that could possibly improve their daily living. The child's age is an important indicator of the level of stress the parents may experience. Parents of infants or young children with ID experience lower levels of depression as compared to those with pre-school and adolescent children. As our sample had a majority of children between 1 and 5 years, behavior was identified as the most difficult part about parenting such children. Previous studies have shown that the most important issue raised by the caretakers was of training them to take care of themselves and manage their environment effectively. This mainly includes the specifics of everyday living including dressing, eating, toilet training etc. The inability of the child to survive in the society independently adds to the stress of their parents[23].

In order for them to get appropriate care, the health of the caregiver becomes very important. Therefore, it is absolutely essential to screen parents of such children and introduce interventions at individual and community level to counter it at an early stage[24]. The family can serve as a buffer for parental stress if they are cooperative and assist the parents in their daily activities. For the ID child, improving activities of daily living and increasing autonomy like speech and occupational therapy

early on would enhance the process of development which is otherwise delayed. Previous studies have shown that interventions brought about early seem to be the most effective and hence there is a need to develop feasible, cost-effective, community level interventions, which can be integrated into existing healthcare systems[25]. Our study had a few strengths firstly an appropriate sample was inducted. The questionnaire was filled out by conducting interviews in the local language. Sample was collected from various places to get opinions from a diverse group of people. However limitations cannot be ignored. Non Probability sampling technique was utilized for sampling collection and data collection tool except the depression portion was not validated.

Apart from the interventions made for the affected children and parents, there is one required at the level of the health care providers including physicians, nurses and also school teachers. It is very important for the teachers to understand these children and treat them accordingly.

CONCLUSION

Majority of the parents of intellectually challenged children are suffering from depression. The major risk factors associated with the parents included gender, educational status, family income and the number of children they had. From the child's aspect on the other hand, age, severity of disability and hence the degree of dependency of the child on the parent determined the severity of depression. Most common strategy identified to overcome depression was praying but exercise proved to be the more effective one. Society and doctor's role were also important determinants of the way parents reacted to their child's disability.

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