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Psychopathology and Quality of Life in Parents of Children with Specific Learning Disability.

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Abstract:
Background: *Parents dealing with their child's specific learning disability go through a stressful experience and have to put lot more effort physical and emotional than regular parenting, putting their mental well-being at risk.*
Aims: *To assess the psychopathology and quality of life in parents of children with specific learning disability, and correlate the effects of socio-demographic factors.*
Methodology: *100 consecutive consenting parents of children with diagnosed specific learning disability were interviewed in learning disability clinic. A semi structured proforma, SCL 90 R scale and WHO QOL-BREF scale were used for assessment.Data obtained was analyzed using appropriate statistical tests.*
Results: *The mean age of parents was 40.51±5.84 years. 41% of parents considered it to be a major problem. Obsessive compulsive, anger hostility & depression were the three subscales with highest mean distress index. 42 of 100 parents had general symptom index suggestive of significant psychopathology. Somatization was higher in mothers. Physical, psychological and environmental quality of life was better in higher educated parents. Physical, psychological and total quality of life has inverse correlation with psychopathology subscales and general symptom index.*
Conclusion: *At least 2/5th of parents have significant psychopathology in our sample.Mothers tend to manifest somatization more than fathers. Education, perception of problem and gender influence the quality of life in parents and some aspects of psychopathology. Quality of life deteriorates with worsening of psychopathology in parents.*
Keywords: *Learning disability, Parents, Psychopathology, Quality of life.*

I. Introduction

Specific learning disability is an invisible disability which affects not only the child, but the immediate caregivers and school environment too. Specific learning disability affects 5 to 15 % of the population. [1] The associated problems add to creating difficulties for the child, both at home and school. The care of the child involves various assessments, therapies and at times medications for co morbidity. Handling all these issues at a single time gets tough for both parent as well as child and may have negative psychological impact. The parents end up investing most of their time and energy in the child's special needs, leaving them with little for themselves.

When the parents are informed about their child's disability, the loss of the ideal child of their imagination and the discrepancy between these expectations and reality causes feelings of grief and loss. [2] The presence of a disabled child causes profound changes in the family, with impact of anxiety and depression on parents and on their quality of life being considerable.[3] It has been assumed by researchers that the acceptance process of parents of physically disabled children would be easier than the acceptance process experienced by parents of children with invisible disability as learning disability. [4]Both parents may experience great stress as they adapt and learn to care for their special child. However, it is clear that women caregivers, the mothers, inevitably are exposed to more stress than the fathers. Caregiver stress is the emotional and physical strain of care giving. It can be manifested in many forms like frustration, anger, guilt, loneliness, and exhaustion. Caregivers may be prone to depression due to the perceived inability of the caregiver to provide the care needed and, grief, fatigue and changes in social relationships. They may also experience physical health problems and fatigue. [5] A recent Irish study showed high levels of objective and subjective caregiver strain in caregivers of learning disability with most of them receiving inadequate support.[6]

However over time families learn to adapt to the stress of their lives, sometimes with the help of services for facilitation of the process, though some families are at greater risk than others for experiencing extreme stress. [7]The parents themselves may be suffering from psychiatric disorders, either an effect of the strains of managing a child with specific learning disability or a genetic predisposition, which can worsen the interactions between parent and child and the quality of life.

For a family with a special child, factors as – communication styles, hardiness, family cohesion, and perceived adequacy of social support – all contribute in ability to deal with the stress resulting from having a child with special needs.[8] Parents need to be nurtured and praised to help them nurture and praise their children. [9] Individually parents go through a difficult time dealing with the situation starting from being informed about the disability in their child, therapy, expenses, accepting the situation, and many more issues. The present study is undertaken for a better understanding the condition of parents with a learning disabled child and psychological impact of the diagnosis of their child.

II. Materials And Methods

The study was conducted in Learning Disability clinic of the Department of Psychiatry in a tertiary care teaching hospital in Mumbai.Parents of the 100 children diagnosed with Specific Learning Disability were interviewedfrom Learning Disability clinic of Psychiatric outpatient department. Sampling was purposive and each parent was briefed about the study and its objective before a written informed consent was obtained.The proposal of study was cleared before the commencement of study by institutional ethics committee.Parents of the children diagnosed with Specific Learning Disability who were willing to participate in the study and gave informed consentfor the study, were included in the study. Those parents who were already been diagnosed with psychiatric illnesses,suffering from any major or chronic medical illness and those whose childrenwere suffering from any other psychiatric or chronic medical illness were excluded from the study.

The information gathered from the parents was documented in a specially designed case record form for the purpose of the study. It had socio-demographic variables and responses by the parent for the standardized instruments used for the study namely Symptoms Check List -90 R and WHOQOL-BREF.

Symptoms Check List -90 R (SCL-90R) is a screening instrument for general psychopathology symptoms. The scale was developed by Derogatis[10]and consists of 90 self-rated items responses of which are scored on 0 to 4 continuums. The SCL 90 R covers nine symptoms dimensions: somatization, obsessive compulsive symptoms, interpersonal sensitivity, depression, anxiety, anger hostility, phobic anxiety, paranoid ideation and psychoticism along with a General Symptomatic Index (GSI). The internal consistency coefficient alphas for the nine symptom dimensions ranged from 0.77 for Psychoticism, to a high of 0.90 for Depression. Studies shows that a GSI of >0.57 indicated significant general distress. [11]

WHO Quality of Life-BREF (WHOQOL-BREF) is an abbreviated version of the WHO QOL-100. It is a self-administered instrument; however respondents who have difficulty due to illiteracy can be assisted by an interviewer who reads the question. It takes into consideration physical and psychological factors, social relationships and environmental domains of quality of life and gives sub scores on above mentioned domains ranging from 0 to 100. Internal consistency of WHO QOL-BREF for Indian patients ranges from 0.63 to 0.84 and it performs well on preliminary tests of validity.[12]For the purpose of our study a value of less than 50 % of the total score was considered as poor quality of life.

The collected data was analyzed using SPSS-20 software under the guidance of a statistician. The data was presented using mean, median, standard deviation and interquartile range. Mann-Whitney U test was used for comparison of data as it failed normality test (Shapiro-Wilk). Pearson correlation coefficient was used for correlating continuous variables. P value of less than 0.05 was considered statistically significant.

III. Results

We interviewed a total of 100 parents for the study, of which 68 were mothers. Outof 100, 69 had a male child suffering from specific learning disability. Out of 100 parents, 48 were educated up to a bachelor degree or more. The mean age of parents was 40.51±5.84 years (Mothers- 39.63±5.7, Fathers- 42.38±5.8). Twenty parents reported facing academic difficulties similar to their child diagnosed with specific learning disability. We asked the parents about their perception of disorder of their pal, 41 of them considered it to be a major problem and for rest of parents it was minor or non-significant problem.

The mean distress index for each subscale was obtained, Obsessive Compulsive subscale emerged with highest mean distress index followed by Anger Hostility & Depression (Table 1). 42 of 100 parents had General Symptomatic Index greater than 0.57 which is cut off for significant psychopathology. We compared psychopathology and quality of life according to gender, education and perception of disorder as a problem and few significant differences were noted (Table 2). The correlation between psychopathology and quality of life was negative across the subscales and significant largely (Table3).

IV. Discussion

Parenting is like a full time job which requires high level of dedication and is full of challenges. When it comes to parenting a child with additional needs then it's a full time job with regular overtime and next level of challenges. Though parenting is a joint responsibility of mother and father of the child, mothers are traditionally more involved in caring for the children. However with changing times and social norms more women getting out of home for work the responsibility is being shared equally in many if not all families. Our study had more than 2/3rd mothers who brought the child for consultation suggesting still a higher involvement of mothers in caring for the child. In India the awareness about of specific leaning disability is low and in nascent stage, restricted to the curious and privileged parents. The number of undiagnosed children is high due to both lack of infrastructure,very few specific learning disability testing centers as well as lack of awareness in community at large. This clearly reflects in our study population which has almost half of parents with bachelor's degree which is clearly higher than the average educational background of Indian society. It is probably because the underprivileged sections of society may not be aware of it and simply assuming their child to be poor in studies and not asking the question "why?"

The mean age for the sample was 40.51±5.84 years, similar age range was noted by other studies on parents of children with Specific Learning Disability ranging from 42.6 years[13] to average mother's age 40.14 years.[14] Out of the 100 parents assessed 20 had a history resembling learning disability; this finding could be contribution to already known fact that Specific Reading Disorder has a clear evidence of genetic basis. [15] The perception of parents about their child's illness was variable with majority considering it to be a minor or non-significant issue. The specific learning disability affects academics of child majorly but this may lead to catastrophic consequences in few if not all owing to discrimination, teasing, blaming of the child by classmates or others. The perception of majority of parents can be interpreted in two ways either they be ignorant and uninformed about the nature of child's disability or the faith and confidence of the parent in ability of the child and self to overcome the hurdle.

Having said about the stress of parenting a child with specific learning disability it is important to know that the stress can manifest as psychopathology differently in different individuals. The mean distress indexof obsessive compulsive feature was highest among all the psychopathology scales followed by anger hostility and depression in that order. Parents of children with developmental disability do exhibit depressive symptoms[16] and psychological distress is a common presentation for caregivers of children with pervasive developmental disorders. [17]Most mothers develop mild levels of anxiety by the time specific learning disability is diagnosed in their child and these anxieties are mainly related to their child's poor school performance, behaviour, and future prospects in life; and making visits to doctor for their child's assessment. [14] As per best of our knowledge obsessive compulsive features have never been documented as a manifestation of psychopathology in parents of specific learning disability.

In our study we compared psychopathology between genders of parents, a trend of higher distress indices across psychopathology was seen, with somatization being significantly higher in mothers than fathers. Women tend to have higher somatization than men.[18] Also a study [19] on parents of children with congenital heart disease reported higher somatization in mothers than fathers while dealing with stressful situations. Somatization in general is an expression of stress especially when the person cannot verbalize it[20]and there is a close relationship that somatization disorder has with anxiety and depressive disorders with a linear relationship between numbers of somatic and othersymptoms of distress. [21] Hence deductively it can be stated that mothers perceived more stress than fathers. Somatization was also noted to be higher, though statistically not significant($p = 0.057$), in parents perceiving their child's specific learning as a major problem. The higher somatization could be due to the perception of the problem as"major" leading to more stress. [22]Higher stress could lead to more somatization, as suggested by a study which reports significant positive correlation between level of perceived stress and level of somatization. [23] The parents with lower education and perceiving the situation as major problem had significantly higher distress index for interpersonal sensitivity. Also anger hostility was significantly higher in those perceiving the situation as major problem. It appears that the education enables parent to handle their relationship better. Relationships and anger issue were also better with parents having relatively better perception about the environment and child's condition in our study population. The worse perception of situation can result in negative consequences and outcomes. [24]

Quality of life was studied across domains and Physical, Psychological and Environmental domains of quality of life scores were significantly better in parents who were educated to graduation level or above. The parents of children with learning disability who were educated up to matriculation were found to have worse psychological and environmental quality of life than those having studies up to diploma or degree level in study by Karande and Kulkarni. [13]The difference in quality of life scores could be due to better understanding of the situation and also better ability to search for available solutions to the child's learning disability. Education equips one not only to be resourceful and make better use of available resources but also increases the availability of support structure to get over and deal with the problems of life. Similarly those perceiving their

child's disorder to be a minor problem had better scores on quality of life scale overall with exception of physical quality of life. It won't be exaggeration to say that perception about the events and situation in life may alter the quality of life.

Our study noticed the physical quality of life was significantly better in fathers, higher educated parents and in those considering learning disability a minor problem. A study [13] focused on quality of life in parents of dyslexic children, using WHO QOL 100 scale, found that being educated up to class standard X was significantly associated with a lower Physical domain score. Same study also found that education up to a university diploma or degree level was significantly associated with a higher spiritual domain score of WHO QOL 100.

In this study physical, psychological and total quality of life had significant negative correlation with all the subscales and GSI of SCL 90. Similar findings were noted by study on caregiver burden in learning disability, [25] where significant negative relationship between the quality of life and stress experienced by parents was noted,with no gender differences,both fathers and mothers had low quality of life scores, though our study lower physical quality of life was noted only in mothers.

V. Conclusion

The highest psychopathologies in parents of children with specific learning disability are obsessive compulsivity, anger hostility and depression with mothershaving higher somatic presentation of stress than fathers. Hence sensitization of mental health professionals towards psychological distress of parents of children with specific learning disability is needed especially somatic complaints in females.Also psychopathology as well as quality of life varieswith parent's educational level and perception of situation which can be minimized by creating better awareness regarding the Specific Learning Disability and more importantly about available therapies and help. With the noted extent of psychopathology in parents, whiledealing with child's disability, it's highly expected to include parents as well for evaluation while the child is being given therapy for Specific Learning Disability.Quality of life has a negative correlation with psychopathology. Fathers, parents with better perception of the situation and those with better education had better quality of life scores. Keeping psychopathology to a minimum and better awareness about Specific Learning Disability to improve perception could be a way to improve quality of life in parents.

VI. Limitations

Study being conducted in an urban setting, study population did not have representative for rural population, which India mostly comprises of.The cross-sectional design of the study fails to study the impact over the lifetime of parents but catches at single point.Study has a small sample size. It's a hospital based study than the community based one.

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	Pages	Figures	Tables	Words
Abstract	01	00	00	237
Text	16	00	03	2586

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Tables:

Table 1: Scl 90 R & Who Qol-Bref Subscale Scores For The Study Population

Variables	Mean	SD	Median	IQR
Somatization	0.56	0.56	0.37	0.73
Obsessive Compulsive	0.79	0.68	0.60	0.80
Interpersonal Sensitivity	0.69	0.65	0.44	0.78
Depression	0.73	0.68	0.46	0.92
Anxiety	0.52	0.55	0.30	0.70
Anger Hostility	0.78	0.76	0.50	0.96
Phobic Anxiety	0.36	0.52	0.14	0.42
Paranoid Ideation	0.70	0.68	0.50	0.99
Psychoticism	0.35	0.48	0.15	0.58
General Symptom Index	0.62	0.53	0.48	0.65
Physical QOL	70.32	13.44	69.00	18.00
Psychological QOL	64.21	15.37	66.00	19.00
Social Relationship QOL	70.35	15.78	75.00	23.50
Environmental QOL	65.76	13.99	63.00	19.00
Total QOL	271.21	46.43	270.00	54.50

SD- Standard deviation, IQR- Interquartile range, QOL- Quality of life.

Table 2: Comparison of psychopathology and quality of life in parents based on gender, education and perception of problem

Variables	Gender of parent				Education level of parent				Perception of disorder as problem			
		N	Median (IQR)	P value		N	Median (IQR)	P value		N	Median (IQR)	P value
Somatization	Mother	68	0.42 (0.81)	0.035*	Low	52	0.46 (0.9)	0.101	Minor	59	0.33 (0.67)	0.057
	Father	32	0.25 (0.4)		High	48	0.33 (0.48)		Major	41	0.42 (1. 04)	
Obsessive Compulsive	Mother	68	0.65 (0.98)	0.08	Low	52	0.6 (1.1)	0.543	Minor	59	0.5 (0.7)	0.387
	Father	32	0.45 (0.78)		High	48	0.6 (0.7)		Major	41	0.6 (1.05	
Interpersonal sensitivity	Mother	68	0.44 (0.89)	0.531	Low	52	0.715 (0.86)	0.037*	Minor	59	0.44 (0.66)	0.025*
	Father	32	0.44 (0.66)		High	48	0.44 (0.52)		Major	41	0.77 (0.89)	
Depression	Mother	68	0.53 (0.92)	0.149	Low	52	0.61 (1.15)	0.188	Minor	59	0.46 (0.77)	0.187
	Father	32	0.3 (0.9)		High	48	0.46 (0.53)		Major	41	0.69 (1.19)	
Anxiety	Mother	68	0.35 (0.7)	0.257	Low	52	0.4 (0.88)	0.477	Minor	59	0.3 (0.6	0.297
	Father	32	0.2 (0.6)		High	48	0.3		Major	41	0.5 (0.8)	

							(0.58)					
Anger Hostility	Mother	68	0.5 (0.96)	0.165	Low	52	0.5 (1)	0.14	Minor	59	0.33 (0.66)	0.039*
	Father	32	0.33 (0.63)		High	48	0.5 (0.69)		Major	41	0.66 (1.17)	
Phobic Anxiety	Mother	68	0.14 (0.42)	0.443	Low	52	0.14 (0.54)	0.444	Minor	59	0.14 (0.43)	0.88
	Father	32	0.14 (0.43)		High	48	0.14 (0.42)		Major	41	0.14 (0.42)	
Paranoid Ideation	Mother	68	0.58 (0.99)	0.284	Low	52	0.58 (1)	0.808	Minor	59	0.5 (0.67)	0.775
	Father	32	0.33 (0.83)		High	48	0.415 (0.75)		Major	41	0.66 (1)	
Psychoticism	Mother	68	0.2 (0.58)	0.111	Low	52	0.2 (0.58)	0.902	Minor	59	0.1 (0.4)	0.157
	Father	32	0 (0.4)		High	48	0.1 (0.58)		Major	41	0.2 (0.8)	
General Symptom Index	Mother	68	0.52 (0.65)	0.11	Low	52	0.58 (0.89)	0.166	Minor	59	0.43 (0.48)	0.088
	Father	32	0.385 (0.43)		High	48	0.45 (0.47)		Major	41	0.6 (0.63	
Physical QOL	Mother	68	69 (22)	0.048*	Low	52	69 (23)	0.047*	Minor	59	75 (12)	0.004*
	Father	32	75 (12)		High	48	69 (12)		Major	41	69 (19)	
Psychological QOL	Mother	68	63 (25)	0.322	Low	52	63 (30)	0.016*	Minor	59	69 (25)	0.026*
	Father	32	69 (19)		High	48	69 (25)		Major	41	56 (25)	
Social Relationship QOL	Mother	68	72 (25)	0.988	Low	52	69 (19)	0.162	Minor	59	75 (12)	0.271
	Father	32	75 (16)		High	48	75 (12)		Major	41	69 (19)	
Environmental QOL	Mother	68	63 (19)	0.855	Low	52	63 (19)	0*	Minor	59	69 (12)	0.004*
	Father	32	69 (19)		High	48	69 (18)		Major	41	63 (19)	
Total QOL	Mother	68	269 (44)	0.385	Low	52	263 (66)	0.004*	Minor	59	281 (44)	0.009*
	Father	32	275 (50)		High	48	275 (50)		Major	41	257 (51)	

IQR- Interquartile range, QOL- Quality of life, Level of education low- Educated less than bachelor's degree, Level of education high- Educated at least upto bachelor's degree. *P<0.05.

Table 3: Correlation between quality of life and psychopathology.

		Physical QOL	Psychological QOL	SocialRelationship QOL	Environmental QOL	Total QOL
Somatization	Pearson	-0.53	-0.40	-0.20	-0.29	-0.44
	P value	0.00*	0.00*	0.05	0.00*	0.00*
Obsessive Compulsive	Pearson	-0.53	-0.64	-0.25	-0.30	-0.53
	P value	0.00*	0.00*	0.01*	0.00*	0.00*
Interpersonal Sensitivity	Pearson	-0.47	-0.47	-0.22	-0.26	-0.44
	P value	0.00*	0.00*	0.03*	0.01*	0.00*
Depression	Pearson	-0.50	-0.56	-0.37	-0.30	-0.55
	P value	0.00*	0.00*	0.00*	0.00*	0.00*
Anxiety	Pearson	-0.48	-0.45	-0.27	-0.28	-0.44
	P value	0.00*	0.00*	0.01*	0.00*	0.00*
Anger Hostility	Pearson	-0.32	-0.35	-0.30	-0.14	-0.34
	P value	0.00*	0.00*	0.00*	0.15	0.00*
Phobic Anxiety	Pearson	-0.22	-0.42	-0.24	-0.17	-0.34
	P value	0.03*	0.00*	0.02*	0.10	0.00*
Paranoid Ideation	Pearson	-0.33	-0.47	-0.25	-0.22	-0.38
	P value	0.00*	0.00*	0.01*	0.03*	0.00*
Psychoticism	Pearson	-0.45	-0.44	-0.19	-0.24	-0.38
	P value	0.00*	0.00*	0.06	0.01*	0.00*
GSI	Pearson	-0.53	-0.56	-0.31	-0.30	-0.53
	P value	0.00*	0.00*	0.00*	0.00*	0.00*

QOL- Quality of life. *P<0.05.