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DETERMINANTS OF PSYCHOLOGICAL WELLBEING IN MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITY

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ABSTRACT

Objective and Background: *The purpose of current study was to investigate the significance of some familial variables in determining depression, anxiety and stress in mothers of children with intellectual disability. These variables include age of the child with intellectual disability, and the presence of other siblings, specially with reference to their gender.*
Hypotheses: *It was hypothesized that there will be a significant difference in level of anxiety, stress and depression among mothers of children with different age groups i.e. children with ages 5 -7 years;8 - 10 years; and 11 - 13 years. It was further hypothesized that there will be a significant difference on above stated variables among mothers having only child with intellectual disability; having only female children other than intellectually disable child; and mothers having both male and female children other than child with intellectual disability.*
Sampling and Method: *Sample of mothers (age ranges between 25 to 45 years) of children with intellectual disability, between ages 5 to 13 years was categorized according to predetermined criteria for screening on two variables, that is, 1) Age of their child with intellectual disability, 2) Number and gender of siblings of their child with intellectually disability. Depression, Anxiety and Stress Scale (DASS, Lovibond & Lovibond, 1995) was administered to find out the level of depression, anxiety and stress among mothers of children with intellectually disability.*
Results: *Results indicate that there is a significant difference among three groups, i.e. 1) mothers having only child, 2) mothers having daughters only other than the child with intellectual disability, and 3) mothers having both male and female children other than the child with intellectual disability, on the variables*

of depression, anxiety and stress (F (2, 75) =18.794, p<.001; F(2, 75) =41.924, p<.001; F(2, 75) =6.603, p<.002 respectively). Results reflect the least anxiety, depression and stress in group having both male and female children other than the child with intellectual disability. Further findings reported that there is significant difference among age groups on the variables of depression and stress (F (2, 75) =4.517, p<.014; F (2, 75) =12.780, p<.001 respectively), with higher means associated with the 5 to 7 years old group of children, however, difference on variable of anxiety was found insignificant (F (2, 75) =.720, p>.05).Further implications and limitation were discussed.

***Keywords**: Depression; anxiety; stress; Intellectual disability; mothers*

INTRODUCTION

Intellectual disability of child is whole life stigma for parents specifically for mothers. A number of mothers experience the emotional pain to learn that their child is not as smart as other children and that the situation is irreversible and there is no cure of the problem. The lack of awareness of how to manage the problem adds up the tension associated with the negative affect associated with the disability of the child. Many become the victim of fear of criticism and negative evaluation.

Mothers may have various challenges to face in addition of the challenges of motherhood when they face the situation of rearing up a child with intellectual disability. The criticism from the society and sometimes the family, the behavioral and emotional problem of the child, the extreme dependency of the child on mothers as the major caring figure in the family, the excessive work pressure to meet the demands of other family members as well along with the child with intellectual disability, the lack of awareness regarding how to rear the child with challenges, disturbance in relationship with spouse, coping with unrealistic expectations regarding child's progress, the guilt and hopelessness as well as apprehensions about the future of the child are some of many concerns a mother may have in a society where there are less privileges available for people with such disabilities.

Some of mothers have to do a lot of efforts for their children treatment and sometimes their efforts hardly bore fruitful results, this decreases mothers'

motivations and interests about child's treatment. Sometimes mothers feel hopeless and helpless, feel guilty, perceive low mood most of the time, isolation, lack of interest in activities, irritability and lack of leisure activities. Mothers also develop some personal views about child's disability like' it is a punishment for me', 'it is result of my sins which I committed in the past' and that 'it is because of partner's misfortune'. These and similar factors may be associated with the often reported symptoms of depression, anxiety and stress in mothers of children with disability (Bumin, Gunal, & Tukel, 2008; Ellis & Hirsch, 2000; Ganong, Doty, & Gayer, 2003).

The common associated problems of intellectually disability are speech deficits, motor problems, epilepsy, Down's syndrome and cerebral palsy as well as learning disability, cognitive, perceptual, behavioral and emotional. Both these medical and psychological problems of children affect mothers' mental health badly. Parents bear costly treatments, frequent or unexpected clinics visit, continuous child look after and limited allocated time for other family members and self grooming and it gradually turns into stressors and these continuous stressors causes depression and anxiety related disorders among mothers (Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003; Ryde- Brandt, 1990).

Previous studies reported mothers of intellectually disabled children are more vulnerable toward mental health problems (Baxter, Cummins, & Yiolitis, 2000; Maurice, Feldman, Varghese, Ramsay, & Rajska, 2002). Some other studies reported psychological stressors among these mothers is major cause of emotional disturbance (Olsson, & Hwang, 2001; Weiss, 2002). Mother perceived high level of depression, anxiety and stress when due to increased busy schedule and engagement in activities related to treat a disable child left very less amount of time for herself (Little, 2002; Murphy, Bruno, Abbeduto, Giles, Richmond, & Orsmond, 2004). This is also observed through previous studies that the behavioral, emotional and social problems demands mother's amount of time, motivation and continues supervision; failure to do the tasks perfectly may result in dissatisfaction and mother becomes depressed and may develop hopelessness (Lim, & Lee, 2007; Mullins, Aniol, Boyd, Page, & Chaney, 2002; Rodrigue, Morgan, & Geffken, 1990; Smith, Oliver, & Innocenti, 2001). Work with intellectually disabled children is not a normal or specific time bound job but it is the throughout life job for mother and the tiring nature of this endless job increases mental health risks and lessen satisfaction with life (Abbas & Khanam, 2013).

Some others perspectives like dearth of knowledge or lack of awareness among mothers, negative perception or perception according to some cultural beliefs and societal negative attitudes toward special children make the mothers more vulnerable to mental health problems (Duvdevany & Abbound, 2003; Greenberg, Seltzer, Krauss, & Kim, 1997). In our culture, some parents are not fully aware about the nature of problems in children due to intellectual disability and they have few negative or cultural perceptions and beliefs about it. Sometimes parents don't like to move in gatherings with intellectually disabled child because they feel embarrassed and fearful about society's negative evaluation and criticisms. These perceptions also affect parents' interpersonal relationships and socialization. Previous studies reported poor social support system increases the intensity of mental health problems in mothers (Franks, Cronan, & Oliver, 2004; Roth, Mittelman, Clay, Madan, & Haley, 2005). Similarly, in Korea when they came to know the public perspective toward mental retardation has become very negative in general public's mind that was almost similar to our culture, Korea started to spread awareness or education about intellectual disability in public and public concept was now completely changed into realistic sense after continuous struggle of 15 years (Cho, Singer, & Brenner, 2000; Kyun, 2000).

Keeping in view the cultural practices there are few familial variables one may interest to see the association of them with psychological problems. Intellectually disabled children's age has its significance in this instance. For example early age of child is considered more stressful life for mothers. Similarly, mothers of intellectually disabled children perceive more stressors at early age of children because of varieties of reasons, first of all when mother comes to know about child's disability that is very shocking for her, she has to do a lot for her child. In early age of child, mother used to pay more attention and care despite all things. Therefore, continuous efforts and struggles make the mothers more stressed and panicky. Though every age has its own difficulties and challenges, early ages meant to be more dependent on mothers. Further in early years it may be hard for parents to accept the short coming to which they usually adapt or adjusted in later ages and thus lesser distress is expected to be associated with later ages.

For every parent having a child with disability may be trauma and it is more painful for those parents who have only child and child is intellectually disabled. The parent of an only child though have less tiresome routine as they have less kids to be taken care of, they however have insecurities related to the

future of the child, as who will take care of the child after them. For having other male children in the family they usually believe that the child may be taken care in a traditional joint family system of Pakistani culture. However, there are other stressors associated with having more kids including expectations of other children for similar attention as the sibling with intellectual disability enjoys. Difficulty in managing their expectations and resulting jealousy or comparison may result in conflicts among siblings as well as growing parental distress in mothers.

Present study thus aims to investigate the level of depression, anxiety and stress among mothers according to the age of intellectually disabled children and to investigate the difference among mothers according to their numbers of children other than the child with intellectual disability on the variable of depression, anxiety and stress.

METHODOLOGY

Participants

Total sample was comprised of 78 mothers. Sample was collected from different special schools and rehabilitations centers of Karachi. Sample was categorized after screening the mothers on the variables that of, 1) age of children with intellectual disability and, 2) numbers of siblings of intellectually disabled child. Criterion one, age range of children was between 5-13 years (28 children were 5-7 years, 22 children were 8-10 years & 28 children were 11=13 years). Criterion two, sample of mothers was categorized as having only child *(N*=18), mothers having only female children other than intellectually disabled child (*N*=25), and mothers having both male and female children other than intellectually disabled child (*N*=35). The age range of the mothers was 25-45 years (*M*= 36.59; *SD*= 6.97 years).

Measures

Depression Anxiety and Stress Scale (DASS)

The Depression, Anxiety and Stress Scale (DASS), 42 items was developed by Lovibond and Lovibond (1995) was administered to find out the level of depression, anxiety and stress over period of one week. DASS, 42 items scale is comprised of three sub-scales which are depression, anxiety and stress.

Each sub-scale is comprised of 14 items. Each item of DASS is scored from 4-point frequency rating scale from 0 (did not apply to me) and 3 (applied to me all the time). Subscales scores calculated by the sum of all items of depression, anxiety and stress respectively. Scores from 0-9, 0-7 and 0-14 are considered to be normal range for depression, anxiety and stress. Scores between 10-13, 8-9 and 15-18 are considered to be mild level of depression, anxiety and stress respectively. Similarly, scores from 14-20, 10-14 and 19-25 indicate moderate level of severity for depression, anxiety and stress respectively. However, depression, anxiety and stress score from 21-27, 15-19, and 26-33 indicate severity level of psychological distress. Scores from 0-9, 0-7 and 0-14 are considered to be normal range for depression, anxiety and stress. In addition, extreme levels of psychological distress indicate by above 28 scores for depression, 20 for anxiety and 34 for stress.

Procedure

Initially, permission was taken from authorities. Purposive sampling technique was used to recruit the participants. Researcher briefly explained the nature of the study and its importance to understand mental health issues of mothers and to formulate treatment advances with the help of study results. Researcher also reassured that the information given will be confidential and their identity will never be disclosed. Participants were asked to read out a consent form and sign it if they were willing to participate. After getting brief demographic information short interview was conducted and then Depression Anxiety and Stress Scales were administered individually.

Statistics Analysis

Data was scored according to manual and transferred to excel sheet for statistical analysis. Data was statistically analyzed through SSPS, Vol.12. Mean and standard deviation was computed for the demographic description and one way ANOVA was used to find out the difference among the age and gender.

RESULTS

Table 1
Demographic Distribution of Sample

Demographic information	**Categories**	**Frequencies**	**Percentages**	***M***	***SD***
Age				36.59	6.97
Education	Middle	27	34.6		
	Metric	21	26.9		
	F.A	12	15.4		
	B.A	18	23.1		
Socioeconomic	Low	50	64.1		
Status	Middle	28	35.9		

N=78

Table-2Difference among *mothers having child with intellectual disability belonging to different age groups 5-7, 8-10 and 11-13 years, on the variables of depression, anxiety and stress*

Scales	**Age**	***N***	***M***	***SD***	***F***	***P***	***Df***
Depression	5-7	28	29.75	5.29			
	8-10	22	25.90	5.24	104.51	.014	2,75
	11-13	28	25.21	7.15			
Anxiety	5-7	28	24.67	6.37			
	8-10	22	22.90	7.92	0.72	.490	2,75
	11-13	28	22.67	6.04			
Stress	5-7	28	29.17	3.76			
	8-10	22	21.68	5.46	12.78	.000	2,75
	11-13	28	24.96	6.28			

*N=78 * The mean difference is significant at the .05 level.*

Table 3

Post Hoc Test for Depression, Anxiety and Stress according to the age of children

Scales	Gp1	Gp2	*Mean Dif.*	*SE*	*Sig.*
Depression	5-7	8-10	3.84	1.72	.071
		11-13	4.53*	1.60	.017
	8-10	5-7	-3.84	1.72	.071
		11-13	0.69	1.72	.914
	11-13	5-7	-4.53*	1.60	.017
		8-10	-0.69	1.72	.914
Anxiety	5-7	8-10	1.769	1.92	.628
		11-13	2.000	1.80	.510
	8-10	5-7	.1.769	1.92	.628
		11-13	0.230	1.92	.992
	11-13	5-7	-2.000	1.80	.510
		8-10	-0.230	1.92	.992
Stress	5-7	8-10	7.496*	1.50	.000
		11-13	4.214*	1.41	.010
	8-10	5-7	-7.496*	1.50	.000
		11-13	-3.282	1.50	.079
	11-13	5-7	-4.214*	1.41	.010
		8-10	3.282	1.50	.079

*N=78; * The mean difference is significant at the .05 level.*

Table 4

Difference between mothers having only child with disability, only daughters other than the child with disability, and both male and female children other than child with disability, on the variables of depression, anxiety and stress

Scales	Groups	*N*	*M*	*SD*	*F*	*P*	*Df*
Depression	Only child	18	32.44	5.46			
	Only Daughters	25	28.20	5.40	18.79	.000	2,75
	Both child	35	23.42	4.90			

Table contd….

Scales	Groups	*N*	*M*	*SD*	*F*	*P*	*Df*
Anxiety	Only child	18	26.00	5.32			
	Only Daughters	25	28.96	4.99	41.92	.000	2,75
	Both child	35	18.22	4.04			
Stress	Only child	18	28.66	3.83			
	Only Daughters	25	26.72	5.81	06.60	.002	2,75
	Both child	35	23.11	6.19			

*N=78 *The mean difference is significant at the .05 level.*

Table 5

Post Hoc Test for Depression, Anxiety and Stress among groups of mothers with only child, only female child other than the child with disability, with both male and female child other than child with disability

Scales	*G1*	*G2*	*Mean Dif.*	*SE*	*Sig.*
Depression	Only child	Only Daughters	4.244*	1.61	.027
		Both children	9.015*	1.51	.000
	Only Daughters	Only child	-4.244*	1.61	.027
		Both children	4.771*	1.36	.002
	Both children	Only child	-9.015*	1.50	.000
		Only Daughters	-4.771*	1.36	.002
Anxiety	Only child	Only Daughters	-2.960	1.45	.108
		Both children	7.771*	1.36	.000
	Only Daughters	Only child	2.960	1.45	.108
		Both children	10.731*	1.23	.000
	Both children	Only child	-10.731*	1.36	.000
		Only Daughters	-7.771*	1.23	.000
Stress	Only child	Only Daughters	1.946	1.74	.504
		Both children	5.553*	1.63	.003
	Only Daughters	Only child	-1.946	1.74	.504
		Both children	3.605*	1.47	.043
	Both children	Only child	-5.553*	1.63	.003
		Only Daughters	-3.605*	1.47	.043

*N=78; * The mean difference is significant at the .05 level.*

DISSCUSSION

Findings reflect that mothers of younger children with intellectual disability reported higher level of depression, anxiety and stress and these findings are consistent with the findings of previous study (Sajedi, Alizad, Malekkhosravi, Karimlou, &Vameghi, 2010). Mothers of those special children who have age less than seven years were found significantly different from mothers having children between age eight to ten years and mothers having children above ten years of age on variable of depression and stress. This indicates that mothers' stressors start from early age of child and cause depression gradually. Younger children are usually required higher level of attention and care when the child is with any disability the young age becomes more crucial and child may require more attention and care. Extra responsibilities and engagements make mother daily life very stressful and over burdened.

With the passage of time mothers become habitual of child's routine and develop better adjustment and coping abilities gradually. They have better understanding about nature of child's problem. In fact at early age of child mother used to do extra support, care, and attention and mothers also put all efforts for treatment and child betterment. For this purpose she used to visit hospitals or practitioners frequently. Mothers perceive more mental health problems in initial days of awareness or disclosure of child's problem, with anxious observation of child's milestones, problems in motor skills, poor understanding, schooling difficulty and behavioral problems as well. As child grows up and problems started to resolve this decreases mother's stressors (Franks, Cronan, & Oliver, 2004).

Among mothers of children with all age groups was found insignificant difference on variable of anxiety, while mean scores of mothers who have children above age ten were high as compared to mothers of children below age of ten years. This indicates similar anxiety level and preoccupation in mothers of children with intellectual disability across different age groups. Mothers' apprehensions mostly related to child care after their absence. They ruminate how their child can survive, how he or she can manage self independently. The resulting frustrations from child's progress often lead them to distress and helplessness. Mothers' anxiousness about child behavior, preoccupation for worst happening and sensitivity toward criticism with the passage of time might be

changed into chronic stressors and severe depression among mothers (Rudolph, Rosanowski, Eysholdt, & Kummer, 2003).

Findings reported mothers of child with intellectual disability found more anxious, depressed and stressed when the child is the only child of the family, as compared to the mothers who have other children too. For Anxiety and stress however the difference between group with only child and group with only female child along with the child with intellectual disability on the variable found insignificant reflecting cultural stereotypes associated with female gender.

Although mother of only child does not have over workload related to rearing of more children, but lack of expectations, fear associated with future of child and continuous life stressors make them depressed and anxious. In comparison, mothers who have more than one child although one of them is intellectually disable perceive more emotional support than mothers of single child. They not only have more positive life events related to their other children but also they have expectations that their other children might be helpful for taking care of their child with limited skills.

These findings are important in perspective of Pakistani society specially where the burden of rearing a child with special needs is the sole responsibility of parents only. Very less governmental and societal support is available. No quotas for job placements, no special measures or disability friendly environment in any organization is yet established. The dependency of a child with any disability on parents or immediate family may cause distress and resulting associated mental health problems. Only few may have access to counseling services. The facts are indicative of dire need to promote research in special needs of the parents of child with intellectual disability, and to design services meeting these needs.

Conclusion

It is concluded that many familial variables may result in the distress reactions and mental health problems in parents of children with intellectual disability. Parents' beliefs and expectations also play significant role in emotional disturbance. Poor social support system causes depression in mothers as depicted by a number of researches. Lack of education or awareness about disability is also a major factor resulting in distress for both children and their parents. There is also lack of training opportunities as very few institutions are working to train them.

Present study recommended that mothers counseling is very most important to deal with their distress resulting from various psychological factors, and associated psychological problems. Stress management techniques can be helpful for mothers to reduce distress. Family psycho-education is also important to understand the mothers about the root causes of problems, to reduce the stigma of negative perception, and deal with problem effectively. Further, rehabilitations centers, training institutions, awareness programs and psychological education to parents may be helpful to reduce mental health problems and stigma in mothers.

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