



PSYCHOLOGICAL WELL-BEING AND CAREGIVER'S BURDEN AMONG MOTHERS AND FATHERS OF AUTISTIC CHILDREN

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ABSTRACT

INTRODUCTION/OBJECTIVES: Rearing a Normal, typically developing child is stressful for many parents. It could be even more stressful when raising a child with developmental disability like Autism. The present study aims to compare 'Quality of life' (QoL) and 'Burden of care' (BoC) between mothers and fathers of autistic and normal children. It is hypothesized that there is significant difference between mothers and fathers of autistic and normal children on QoL and BoC.

METHOD: The total sample comprised of 225 parents; 107 parents of autistic children and 118 parents of normal children. The scales used are 'Psychological Well-Being' scale by Dr. Carol Ryff, and 'Burden Assessment Schedule (BAS)' by Dr. R. Thara et al.

RESULTS/CONCLUSIONS: The results show that there is no significant difference between fathers and mothers of Autistic children ($t= 0.38, p > 0.1$ and $t= -0.41, p > 0.1$) on QoL and BoC respectively and there is no significant difference between fathers and mothers of Normal children ($t= .64, p > 0.1$ and $t= -0.35, p > 0.1$) on QoL and BoC respectively.

IMPLICATIONS: Although there is wide conceptual and theoretical understanding on the need to determine QoL and BoC of Parents of Autistic and Normal Children, little empirical data is available to support these propositions especially in Indian context. Hence the present study is an attempt to explore the QoL and BoC of Parents of Autistic and Normal Children.

KEYWORDS: Autism, Psychological well-Being, Caregiver, Quality of Life, Burden Of care.

INTRODUCTION:

All parents wish for a healthy baby, but some parents though not by their choice are gifted with a special child, like a child with Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder, Mentally Retarded, and Down syndrome and so on. Some Parents are able to cope up with such a situation whereas, other experience psychological problems (Peshwaria, R. A & Ganguti, R. 1995).

The two distinctive roles of parents include mothering and fathering. A child bestows on both mother and father together or independently, the responsibility of upbringing him. These perceptions may be referred to apparently direct and immediate knowledge associated to their conscious or unconscious experiences by which they initiate and control behaviour enormously. It is important to note that most of the children have a fairly definite clear cut concept of 'father' which differs markedly from their concept of 'mother'. Therefore it appears to be of utmost importance to study perceptions regarding their mothering

and fathering separately as well as parenting as a whole on different dichotomous modes of parenting. Mothering and Fathering are two different types of roles.

The role of mother or the style of upbringing is largely associated with congenial development of personality because the child first comes in contact with mother and always depends on her to satisfy his basic needs. The role of mother shows better control over the children and stands for friendship with less punishment and dominance, symbol of emotional support, interpersonal sensitivity and help and plays an important role in making a person more productive and imaginative. Whereas, patterns of inadequate maternal behaviour seem to be responsible for the problem of children's behaviour and chemical dependence (Bharadwaj, 1995) and tends to inhibit the exploration of child's personality in the environment.

The role of a father or the style of individual's upbringing stands as a bridge by which the child comes into the contact of outside world encourages curiosity and a will to face the challenges of the world and appears as a symbol of assertive, independent, emotional and psychological support in the realization of truth. To love children is predominantly a feature of fathering in non-deviant families and relates to acceptance, satisfaction and differentiating experiences in the children (Khokhar, 1983) that can also be deemed as conditional one because it is acquired or earned by the child's performance of duty, obedience and fulfillment of father's expectations. Whereas, inadequate fathering is usually understood to be a prime source of maladjustment (Erickson, 1963), truancy, guilt, self-devaluation and dependency (Coleman, 1970) and chemical dependence (Bharadwaj, 1996).

Rearing a Normal, typically developing child is stressful for many parents. Its could be even more stressful when raising a child with developmental disability like Autism. Some Parents are able to cope up with such a situation whereas, other experience psychological problems (Peshwaria, R. A. and Ganguti, R. et al., 1995). Many parents experience periods of disbelief, deep sadness and depression and self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt (Gupta and Singhal 2005)

The birth of an autistic child adds situational crisis, one that results from an unanticipated, traumatic event beyond parental control. When parents become aware of their child's disorder they are inevitably shocked and painfully surprised that they must suddenly adjust to the new role as the parents of an exceptional child and they must adjust their self-image to cope with new responsibilities and functions (Gregory, 1991).

The presence of a child with developmental disability in the family calls for a lot of adjustment on the parents and other family members (Peshawaria R, Venkatesan S. 1992). Review of literature revealed that the presence of a child with a disability or illness is stressful for parents especially mothers but most of the studies are done outside India. Studies pertaining to burden of care and Quality of life of mothers and fathers of autistic children are almost nil. In view of this, the present study is taken up with the main objective of doing a comparative study between the parents having an autistic child and those with a normal child, evaluating their quality of life, burden of care and the parent-child relationship.

Hypotheses

Proposed hypotheses of the study are

1. Mothers and Fathers of Autistic Children differ Significantly on QoL
2. Mothers and Fathers of Normal Children differ Significantly on QoL
3. Mothers and Fathers of Autistic Children differ Significantly on BoC.
4. Mothers and Fathers of Normal Children differ Significantly on BoC.

METHOD

Participants

The total sample comprised of 101 fathers and 124 mothers. Out of which, 50 fathers and 57 mothers were having at least one autistic child. The age group of the sample is between 30 - 45 years. The

sample for this study was delimited to accessible, biological mothers and fathers of children from Pune and Mumbai city of Maharashtra, diagnosed with ASD four and above years of age or under by a qualified health care provider. The mother/father of the diagnosed child had to live with, provide care for and raise the child. To reduce measurement error, the sample was delimited to mothers who read as well as understand English/Marathi or both. The diagnosis of the child was within two year of this study and done by a valid and reliable screening tool or multi-professional team during the preschool-age years.

MATERIALS AND PROCEDURE

1. Burden Assessment Schedule (Thara et al, 1998) is used to assess burden of care. BAS is a most frequently used tool to assess the burden of care of psychiatric patients in India. It measures burden in nine areas: (a) Spouse related (b) Physical and mental health (c) External support (d) Care-giver's routine (e) Support of patient (f) Taking responsibility (g) Other relations (h) Patients' behaviour (i) Caregivers' strategy. There are 40 items rated on three point scale. The reliability is 0.80. The validity ranges from 0.71-0.80. The final instrument, therefore, has 40 items rated on a 3-point scale, marked 1-3. The responses would be "not at all, to some extent or very much". Depending on the way the questions are framed, the point for each of these responses would vary.

2. The Ryff's Scales of Psychological Well-Being is a theoretically grounded instrument that specifically focuses on measuring multiple facets of psychological well-being. Quality Of Life Scale has 6 Dimensions Like Autonomy, Environmental Mastery, Personal Growth, Positive Relationship With Others, Purpose In Life, And Self Acceptance.

Presentation Format/Scoring: Items from the separate scales are mixed (by taking one item from each scale successively into one continuous self-report instrument). Participants respond using a six-point format: strongly disagree (1), moderately disagree (2), slightly disagree

RESULTS

Quality of life

Ha1 & Ha2 are analyzed using the following statistical techniques:

Table 1 & 2 respectively showing the Means, SDs and t values for Mother's and Father's of Autistic children (n = 107) and Mother's and Father's of Normal children (n= 118) on 'QoL' Scale

Scale	Autistic Child's	N	MEAN	SD	t-value	p
Total QoL	Father	50	350.64	45.37	0.38	0.71
	Mother	57	347.39	44.03		

Scale	Normal Child's	N	MEAN	SD	t-value	p
Total QoL	Father	51	367.84	36.88	0.64	0.53
	Mother	67	363.36	38.83		

Burden of care

Ha3 & Ha4 are analyzed using the following statistical techniques:

Table 3 & 4 respectively showing the Means, SDs and t values for Mother's and Father's of Autistic children (n = 107) and Mother's and Father's of Normal children (n= 118) on 'BoC' Scale

Scale	Autistic Child's	N	MEAN	SD	t-value	p
BOC Total	Father	50	74.16	10.199	-0.41	0.68
	Mother	57	75.00	10.755		

Scale	Normal Child's	N	MEAN	SD	t-value	p
BOC Total	Father	51	69.00	8.92	-0.35	0.72
	Mother	67	69.52	7.11		

The results show that there is no significant difference between mothers and fathers with respect to the quality of life and level of burden in both study groups (QoL Autistic, t -value=0.38, $p>0.1$; QoL Normal, t -value=0.64, $p>0.1$; BoC Autistic, t -value=-0.41, $p>0.1$; BoC Normal, t -value=-0.35, $p>0.1$).

The results might be contrary to the general notion that mother is more involved in child's upbringing and therefore, would face greater stress associated with looking after the child. Although, mothers are usually the primary caregiver for children, nowadays, fathers also share the task of care responsibilities with their spouses.

Davis and Carter (2008) conducted a study to ascertain the stress experienced by mothers and fathers of toddlers who were newly diagnosed with ASD. Specifically, they explored parenting stress related to the new diagnosis of ASD of their toddler, identified the similarities and differences between mothers and fathers, and examined the associations among the children's disabilities, problem behavior, cognitive level, and parental stress. Results indicated that both parents reported similar high levels of parental burden. A relationship was found between deficit/delays in the social relatedness of the children with overall parenting stress, parent-child relationship problems, and distress for both parents. Similar findings was also reported by Hastings (2003), which reported that both mothers and fathers experienced similar stress levels.

Other studies have findings that are inconsistent with the present study results, which states that mother experiences higher stress in child's upbringing. Studies such as Heller, Hsieh, & Rowitz (1997) reports that mothers spend more time caring for the child with the disability than fathers and that the care giving demands associated with the child's disability lead to increased work absenteeism (Warfield, 2001). Another study conducted by Vidyasagar, N. and Koshi, K. (2010) found that mothers of children with autism experience more stress and tend to cope by either seeking social support, by escaping, or by positively reappraising the situation more frequently than mothers of normal children.

DISCUSSION

This is an important finding as it dashes the general notion that a mother is more likely to face burden and stress compared to father in parenting a child. Its true that the results pertain to urban population of Pune and Mumbai, from where the study population comes from, and it could very well be different situation in rural India. Nevertheless, it speaks about the changing time in urban India, where both mother and father devote significant time in the upbringing of their child.

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