Parental Stress in Raising a Child with Disabilities in India

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ABSTRACT

Purpose: *To determine parenting stress and its determinants among parents of children with disabling conditions in India.*

Methods: *The Parenting Stress Index – short form and a few open ended questions were administered to a convenience sample of sixty-six patient families in July, 2009 in the cities of New Delhi and Faridabad regions of Northern India through six non- governmental organizations (NGOs) that serve children with disabling conditions.*

Results: *Female sex of the child was associated with higher stress related to failure of the child to meet parent's expectations and to satisfy the parents in their parenting role. Parents engaged in more lucrative and prestigious occupations had more stress than parents engaged in less prestigious and lucrative occupations irrespective of their income. Many parents reported receiving little support from their extended families in taking care of their child. Religion was found to be a common coping resource used by the parents.*

Conclusion and Implications: *Higher parenting stress in parents of girls raises the possibility of abuse and neglect. Little support from informal family resources underscores the need for developing formal resources for supporting the parents. The specific resources of parenting stress among parents of different socioeconomic status should be explored in future studies so that appropriate interventions can be planned.*

Key words: *Parenting stress; Childhood disability.*

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INTRODUCTION

Chronic conditions of disability, both medical and emotional, make extra demands on parents, resulting in stress (Tew & Laurence, 1975; Breslau et al, 1982; Stein, 1988; Miller et al, 1992). Mash and Johnson (1983) reported that mothers of children with attention deficits and hyperactivity disorders were more depressed, socially isolated, and restricted in their parental roles than mothers of children with normal behaviour. In addition, they were less attached to their children and felt less competent to deal with them. Perry et al (1992) reported higher stress among parents of girls with Rett syndrome. Beckman (1992) reported higher levels of stress across all domains in parents of children with developmental disabilities. Assessment and amelioration of parenting stress is critical to the welfare and quality of life of the child and the family (Brinchman, 1999). Parenting stress has clinical and social implications, such as marital discord and child neglect and abuse (Mash et al, 1983; Belsky et al, 1985).

It is reported that parenting stress and adaptation depend upon the type of disability, the family's coping resources, and formal and informal supports in the community. While many studies have explored the relation between parenting stress and medical diagnoses, parenting stress depends upon the severity, visibility, unpredictability, number of invasive procedures such as surgeries, and overall type of disability - behavioural, developmental or medical - rather than the medical diagnosis (Breslau et al, 1982). Using the latter approach, Gupta (2007) reported that behavioural and developmental disability was associated with higher parenting stress than medical disability.

The coping resources include "faith in God, energy, self-determination and perception of the situation, and the external resources such as support from family members, relatives, friends, neighbours, professionals, community and Governmental policies and programmes" (Peshawaria et al, 1998). Among the coping resources of the family, family cohesion, religion, spirituality and socioeconomic status have been studied. Lower socioeconomic status of the family is reported to be associated with more stress because of fewer resources (Sameroff et al, 1987). Proximal support from spouse and immediate relatives has been found to promote family adaptation and reduce stress (Hanson & Hanline, 1990). Religious coping has been reported to reduce parenting stress (Bennett et al, 1995).

With respect to support within the community, Dunst and Trivette (1990) described two types of social support systems. **Formal** social supports include

services provided by professionals such as school programmes, parent education specialists, therapists, and respite-care agencies. **Informal** social supports encompass relationships between family members, relatives, neighbours, friends, and community groups.

While parenting stress has been studied in many developed countries, few formal studies have been conducted in developing countries. Shortage of resources, including food, medication, durable medical equipment, and apparel can add to the stress of raising children with disabilities. In conditions of poverty, a child with a disability is regarded as a burden, an evil spirit, and an object of charity without rights, rather than as an unfortunate child (Pal & Choudhury, 1998). The purpose of this study was to assess, both quantitatively and qualitatively, the parenting stress and coping mechanisms and their determinants among parents of children with disability.

METHOD

Sample Selection

The study, conducted in July 2009, collected data from a convenience sample of sixty-six families in the cities of New Delhi and Faridabad in Northern India. Non-governmental organisations (NGOs) in these areas were contacted, which serve children with developmental disabilities, as defined by the United States Developmental Disabilities Act. Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin any time during development up to 22 years of age and usually last throughout a person's lifetime (Section 102(8) of Developmental Disabilities Assistance and Bill of Rights Act, 2000).

Six of the centres that were contacted agreed to participate in the study. The children they served had multiple disabilities, with moderate to severe functional limitations. The parents who accompanied their children on the day the researcher was at the centre were requested to participate. Sixty-six parents were interviewed one-on-one, to complete the short form of the Parenting Stress Index (Abidin, 1995). Due to lack of a-priori hypotheses and the exploratory nature of the study, sample size calculations were not done. Confidence intervals from the analysis, comparable to the normative sample, suggested that the sample size

was sufficient for the exploratory purpose of the study. Apart from completion of the Parenting Stress Index, each parent was asked whether they received physical or social support from their family or community, and to describe in an open-ended manner how they coped with their child's disability. These qualitative and quantitative answers form the basis of this report. While quantitative data generate group statistics, the qualitative approach identifies personal experience and narrative (Padencheri et al, 2011).

Survey Tool

Abidin's (1995) Parenting Stress Index short form (PSI/SF) was used to assess the stress level in the study population. The PSI/ SF is a 36-item scale which is highly correlated with the full length PSI in Total Stress (0.95), Parent Domain (PD 0.92), Child Domain (DC 0.87) and P-CDI (0.73 and 0.5 with the child and parent domains respectively). The parental distress subscale (PD) determines the distress a parent experiences in his or her role as a parent, due to impaired sense of competence, restrictions placed on other life roles, marital conflict, lack of social support and depression. Parent-Child Dysfunctional Interaction subscale (P-CDI) focuses on the parent's perception that the child meets one's expectations and reinforces one's role as a parent. Difficult Child (DC) subscale focuses on a child's behaviour that makes one easy or difficult to handle. The PSI/ SF has been shown to provide indirect support for the generalisability of a 3-factor model of parenting stress among the lower socioeconomic African-American mothers (Mash & Johnson, 1983). Internal consistencies for PSI/SF have been reported to be from good to excellent, and a 3-factor model has been confirmed and validated (Reitman et al, 2002; Diaz-Herrero et al, 2011).

Validation and Analysis

The Parenting Stress Index (short form) was translated in simple Hindi, the common language of people in and around the survey cities, and validated through back-translation by an unbiased Hindi professor. Data were collected anonymously and no identifiers were kept. The data were approved for analysis by the Saint Peters University Hospital Institutional Review Board. The quantitative data was analysed by SPSS version 11. Qualitative data were analysed thematically. The responses of the respondents to the three theme-driven open-ended questions were transformed into three dichotomous variables – support of the family, religious coping and music/media as a favorite coping mechanism.

RESULTS

Majority of the primary caretakers interviewed were mothers of male children from Hindu households, with primary school education, living in joint families, and following labour or clerical occupations (Table 1). High levels of stress were seen in all subscales (Table 2). Mean score in each subscale and the total stress level were above the 90th percentile of the standardisation sample.

Table 1: Demographics of the Study Population

Characteristics	Results	
Religion		
Hindu	74.2%	(49/66)
Muslim	16.7%	(11/66)
Sikh	1.5%	(1/66)
Others	7.6%	(5/66)
Education		
Less than High School	40.9%	(27/66)
Higher Secondary	33.3%	(22/66)
Trade School	3.0%	(2/66)
College	15.2%	(10/66)
Unknown	7.6%	(5/66)
Caretaker of the Child		
Mother	86.4%	(57/66)
Father	6.1%	(4/66)
Unknown	7.5%	(5/66)
Family Structure		
Joint	47.0%	(31/66)
Nuclear	45.5%	(30/66)
Unknown	7.5%	(5/66)
Occupation		
Labour Manual/Skilled	43.9%	(29/66)
Clerical	9.1%	(6/66)
Managerial/Business/ Professional	36.4%	(24/66)
Unknown	10.6%	(7/66)
Sex of the Child		
Male	71.2%	(47/66)
Female	28.8%	(19/66)

The predictor variables - sex of child, income, education, family type and occupation - were used in the regression analysis to determine their relationship to parenting stress (Table 3). A separate regression analysis was conducted with each of the scales from the PSI/SF as criterion variables. Regression analysis did not reveal any significant correlation of total stress and difficult child with the independent variables of occupation, joint family, salary, sex of the child and education (F= 0.52, sig=0.76). Female sex of the child revealed a significant correlation with the PCDI after adjustment for occupation, joint family, and education of the parents (T=2.55, sig=0.014). Occupation of the parent was significantly correlated with parental distress and total stress after adjustment for joint family status, education of the parents, and sex of the child (T=2.84, sig=0.006, T=2.13, sig=0.037).

Table 2: Parental Stress

Stress Domain	Study Parents (n=66)	Abidin	Abidin
	Mean (SD)	Mean (SD)	90th Percentile (Mean+1.2SD)
Parental Distress (PD)	43.7 (9.1)	26.4 (7.2)	36
Parent-Child Dysfunctional Interaction (PCDI)	28.5(7.7)	18.7 (4.8)	27
Difficult Child (DC)	44.9 (10.0)	26.0 (6.7)	36
Total stress	117.05 (20)	72.0 (15.4)	91

Table 3: Parent-Child Dysfunction

	PD	PCDI	DC	TS
ANOVA	F=8.07, sig= 0.006	F= 6.84, sig=0.014	F=0.52, sig=0.76	F=4.55, sig=0.037
Predictors	Occupation T=2.84, sig=0.006	Sex of the child T=2.55, sig=0.014	None	Occupation T=2.13, sig=0.037
Excluded	Joint family, sex of the child, education, annual salary	Joint family, sex of the child, education, annual salary	Joint family, sex of the child, education, annual salary, occupation	Joint family, sex of the child, education, annual salary

Only 32 respondents agreed to answer these questions. Reasons for hesitation were unwillingness to participate in the open-ended segment, lack of time on the part of the respondents or not responding with pertinent information. Nineteen out of the 32 respondents turned to God, mosques and temples, and twenty-eight out of the 32 had turned to the media for help in coping. Twenty-seven out of

32 (84.4%) respondents said that no one helped them to take care of their child (Table 4).

Table 4: Qualitative Responses about Disability Experience (N=32)

Religion as coping mechanism-God, temple, or mosque	59.4% (19/32)
Support from family or friends-"received help from"	15.6% (5/32)
Media as Coping Mechanism-Listen to music or Watch television	87.5% (28/32)

DISCUSSION

Parents in the study experienced very high levels of stress in all domains. As in most published reports, the burden of caring for a child with disability was borne primarily by the mother (Heller et al, 1997; Peshawaria et al, 1998). The data reflected that the female child caused more Parent-Child Dysfunctional Interaction (PCDI). Parent-Child Dysfunctional Interaction subscale focuses on the parent's perception that the child meets one's expectations and reinforces the role as a parent. Reports of the effect of gender on parental stress have been variable in Indian studies. Padencheri et al (2011) reported that marital intimacy is more impaired when the child with disability is female. Tangri and Verma(1992) reported more stress among parents of girls with intellectual disability. However, other studies did not find the gender of the child make an impact on parenting stress (Pal & Choudhury, 1998; Upadhyaya & Havalappanavar, 2008). India is a diverse country with regional subcultures. Although the region from which a family hailed was not asked, Delhi has a lot of immigrants from the neighbouring states of Haryana and Punjab where a female child is traditionally considered more of a burden than a male child (Gupta, 1987). A female child with disability is likely to be considered even more burdensome, raising the spectre of neglect and abuse.

In their role as parents, those who worked as professionals, managers and had small businesses experienced higher stress than those who worked as labourers and clerks, due to impaired sense of competence, restrictions placed on other life roles, marital conflict, lack of social support and depression. This finding is in contrast to most published studies which report higher stress among parents of low socioeconomic status. Higher stress among parents who are engaged in a prestigious occupation may be due to the thwarting of their generally higher expectations of their children, higher perception of shame, frustration

at not being able to restore the condition of the child and more restrictions on their social and professional activities (Duncan et al, 1972). The parents in less prestigious occupations may have lower expectations of their children and may be accustomed to feelings of helplessness (Lewis, 1998; Kumar, 2010).

Three themes emerged from the qualitative part of the study: the unavailability of help from family or the community at large; faith in God and religion; and the use of music and broadcast media to cope with the child's disability. Contrary to general opinion that people in developing or underdeveloped countries live in extended families and close-knit communities supporting one another (Padencheri et al, 2011), almost all of the respondents said that no one helped them. This could be due to the stigma of disability leading to social isolation (Gupta, 1987; Tangri & Verma, 1992; Upadhyaya & Havalappanavar, 2008). The literature on the value of informal support by extended family is variable. Brown (2003) and Pal (2005) both reported a lack of physical support, and Pal found that family support can be a mixed blessing because of increased behaviour problems. In a country where formal social support resources such as parent groups or family counselling are limited, absence of informal support from family and friends can be very stressful. Indians, in general, do not use formal resources even if they are available because of the stigma attached to disability and the damage to the family's honour or izzat (Bhatia et al, 1987; Gilbert et al, 2004).

More than half of the respondents turned to God, mosques and temples for coping, after they had exhausted all avenues of treatment and were told by the physicians that there was "no hope" of a cure. Many researchers from India have reported that people often find relief in religious propitiation and surrender to the will of God when faced with intractable disease and disability (Dalal, 2000; Harrison et al, 2001; Brown et al, 2003; Pal et al, 2005; Farheen et al, 2008; Gupta, 2011). Religion helps to explain and give a meaning to the adversity, and gives hope and purpose to life (Baldacchino & Draper, 2001). It was interesting that almost all respondents stated that they also used the media outlets of music and television to decrease the stress of dealing with the predicament of their loved ones. Music and media have often been used to overcome or divert attention from the stress of managing other chronic diseases and adverse situations (Baldacchino & Draper, 2001; Klitzing, 2003).

Although the study was limited in that a convenience sample was used, and hence the results may not be generalisable to a larger area of India, it highlights a

need for formal social resources such as social workers and agencies, to support parents of children with conditions of disability outside of the family. It also underscores that in certain parts of India the female child with disability is less acceptable to parents than a male child. Although this study did not look into the possibility that female children with disabilities were treated differently from male children with disabilities, future studies could examine the issue of possible neglect and abuse of female children. The finding that parents engaged in more prestigious and gainful occupations had more parenting stress, perhaps because of a wider gap between their expectations and reality, emphasises that all parents of children with disabilities, rich or poor, experience stress and need formal and informal social resources to help them cope.

Since people often turn to religion, it may be advisable for religious institutions and preachers to be trained to provide pastoral counselling to help families cope with the condition of disability. Healthcare providers need to be aware of the religious coping mechanisms which could impact the management of the child's disability. The amount of stress and the lack of support measures in the family may in turn affect not only the condition of the child, but the family as a whole. The specific sources of parenting stress among parents of different socioeconomic status should be explored in future studies so that appropriate interventions can be planned.

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