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The impact of caring for children with mental retardation on families as perceived by mothers in Karachi, Pakistan

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Abstract

Objective: To assess how families perceive the positive and negative impacts of caring for a child with mental retardation.

Methods: The quantitative descriptive study was conducted from January to August 2007 and comprised 54 families attending a private day-care centre for children with special needs in Karachi, Pakistan. The Kansas Inventory of Parental Perceptions was used to assess mothers' perceptions on the impact of caring for a child with mental retardation. Positive contributions, social comparisons with others, understanding of disability and perception of control were assessed. SPSS 16 was used for statistical analysis.

Results: Mothers reported positive contribution to family life as a result of caring for a child with mental retardation (Mean: 2.95±0.37). There was an acceptance of the situation and a trend towards upward favourable comparison with other families (Mean: 3.13±0.07).

Conclusions: Contrary to earlier studies exploring the impact of caring for a child with disabilities having largely focused on negative contributions, the study highlights some positive contributions.

Keywords: Mental retardation, Family life, Children, Pakistan, Positive contributions. (JPMA 63: 1468; 2013)

Introduction

Many children living in low-income countries may be at high risk of acquiring a developmental disability as a result of inadequate deliveries and newborn care practices, micronutrient deficiencies, infections, consanguinity and trauma.^{1,2} Studies on severe mental retardation from low-income countries report a prevalence of higher than 5 per 1000, which is greater than figures reported for high-income countries.² In Pakistan, the reported prevalence of children with mental retardation is estimated to be 19.1 per 1000 for severe mental retardation to 65.3 per 1000 for mild retardation.³ However, negligible attention has been paid towards the development of services to address the needs of this population.⁴

A number of studies assessing the needs of children with disability and their families from middle and low-income countries consistently report the need for more information.¹ In an environment where services to support the development and education needs of children with mental retardation are inadequate, families develop their own coping strategies. In Pakistan, the greater care-giving responsibilities are with the mothers,⁵

who report that they are often blamed for the child's disability by family and members of the community, and that they receive little care-giving support.^{4,5} Parental stress associated with caring for children with mental retardation is high.⁴ In a qualitative study of mothers caring for children with disabilities in a low-income community in Karachi, it was reported that children with disabilities made positive contributions to the lives of their mothers (e.g. greater decision-making power and freedom of movement than peers), but the challenges they faced were still considerable (e.g. no care-giving support, stigma).⁵

In order to develop future models for family support, a greater understanding of both the negative and positive contributions of caring for a child with mental retardation is needed. Families are often likely to report both difficulties with positive perceptions and instruments which help professionals understand both experiences may be useful in developing strategies that are supportive of families and encourage effective coping strategies.^{6,7} In a study from Hong Kong, it was recognised that more support strategies need to be developed to enhance the positive perceptions about the care-giving role of families caring for children with intellectual disability in order to benefit the psychosocial well-being of children and their mothers.⁸ However, there is a paucity of data on the positive contributions of a child with mental retardation on family life from developing countries, including Pakistan.

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The aim of this exploratory study was to describe the impact of caring for a child with mental retardation as perceived by mothers living in Karachi, Pakistan.

Subjects and Methods

The quantitative descriptive study was conducted from January to August 2007 and comprised 54 mothers of children with mental retardation attending a private day care centre for children with special needs in Karachi, Pakistan.

Convenience sampling was utilised after 30% of the population was calculated as the sample size.⁹ The total population was 170, thus 54 mothers were taken as subjects. Data was gathered over a period of 6 weeks during which the researcher stayed at the school from 0800 hours to 1800 hours daily, except weekends. The inclusion criteria comprised mothers who had a child with mental retardation from any economic, social, religious or ethnic group; the mentally retarded child could be a male or a female of age above 6 years, and no restriction in number of siblings and the age of the mother. The exclusion criteria comprised fathers or any other member of the family and mothers who were unable to express or share their experiences which was taken as unwillingness to participate in the study.

In Pakistani context, usually mother is the sole care-giver to the child; therefore only mothers were included in the study. Information about the study was distributed through the children's daily school diary. Interested mothers were able to notify the school and were then contacted by a researcher to arrange an interview. Following discussion about the study, mothers who agreed to participate signed a consent letter.

A demographic questionnaire was used to collect basic information about the family and the participant (the mother). Data on the impact of caring for a child with mental retardation was collected using the Kansas Inventory of Parental Perceptions (KIPP).¹⁰ The inventory consists of 98 items organised into 4 sub-scales, Positive Contribution, Social Comparison, Causal Attributions and Mastery Control, on a 4-point agreement scale: 1 = strongly disagree; 2 = disagree; 3 = agree; and 4 = strongly agree. The format and the response scales remained the same as the original measure. The higher scores indicate that the parent agrees more strongly with the items on the sub-scales; so the higher scores are associated with greater awareness of the perceptions, stronger perception or greater use of the perceptions.⁹ The reported Cronbach's alpha coefficient for reliability and validity for each subscale is 0.56-0.86 and 0.30-0.74 for positive contribution, 0.58-0.78 for social comparison,

0.86-0.87 for causal attribution and 0.68-0.87 for mastery/control. The sub-scale scores were obtained by calculating the means for items on the sub-scale. The instrument was already tested for its reliability and validity in the western context, but it was pilot-tested in the Pakistani context for its appropriateness. The pilot test on five mothers of mentally retarded children was conducted in one of the community schools for mentally retarded children. Mothers were able to understand and comprehend the instrument and were able to respond to the questions asked. Hence, the entire instrument was adopted with no amendments or changes.

Since, to the best of our knowledge, KIPP had not been used in a Pakistani population, the instrument was reviewed by a panel of experts who were familiar with the socio-cultural context and were bilingual in Urdu and English in order to check for conceptual equivalence and clarity as well as consistency in translation.

The inventory was administered in Urdu during face-to-face interviews in a private setting. The procedure took between 40-60 minutes because mothers used this time to share their concerns and issues as care-givers.

Data was analysed using SPSS Version 16.0. Means and standard deviations were calculated for the four sub-scales and the composite score for the KIPP. T-test for independent sample, with unequal sample size, was calculated to verify if the difference in the means of the group which were sub-divided into different categories were significant.

All interviews were conducted after approval by the institutional ethics review committee, and data confidentiality was maintained.

Results

Of the 54 children, 29 (53%) were male and 25 (46%) were female. Besides, 29 (54%) children had mild-to-moderate mental retardation, and 25 (46%) had severe mental retardation. The mean age of the children was 11.2 ± 2.62 years.

Five (9%) mothers were between 20-30 years of age, 34 (63%) were between 31-45 years, and 15 (28%) were more than 46 years of age. Eight (15%) had completed primary school; 7 (13%) middle school; 6 (11%) matriculation; 17 (32%) intermediate; and 16 (29%) had a higher education degree. Besides, 20 (37%) of the mothers reported a household income range of Rs10000-15000 per month (US\$115-175); 5 (9%) less than Rs5000 per month (US\$ 58); and 4 (7%) reported a monthly household income greater than Rs25000 (US\$294). The majority of mothers were housewives ($n=47$; 87%). In addition to a child with

Table: Means and standard deviations of the Kansas Inventory of Parental Perceptions Subscales (n=54).

Components & subscales	Subscale means (X)	SD
Positive contribution	2.95	0.37
Learning through experience with special problems in life	3.39	0.19
Happiness and fulfilment	3.23	0.21
Strength and family closeness	3.17	0.26
Understanding life's purpose	3.22	0.75
Awareness about future issues	3.09	0.10
Personal growth and maturity	3.00	0.30
Expanded social network	2.43	0.55
Career/ Job growth	2.56	0.22
Pride and cooperation	2.44	0.23
Social Comparison	2.99	0.29
Similar comparison	2.91	0.09
Downward comparison	3.29	0.51
Upward favourable comparison	3.13	0.07
Upward unfavourable comparison	2.63	0.78
Causal attribution	2.32	0.71
Fate/chance	3.12	0.41
Special purpose	3.08	0.98
Physiologic causes	1.74	0.19
Professional blame	1.81	0.25
Self-blame	1.86	0.21
Mastery/control	2.13	0.18
Personal control	2.26	0.40
Professional control	2.00	0.49

mental retardation, the majority had 1 (n=17; 32%) or 2 (n=19; 35%) other children.

Mean scores of each sub-scale of the KIPP were calculated (Table). The highest mean was for the Positive Contribution sub-scale (2.95±0.37), followed by Social Comparison (2.99±0.29), Mastery Control (2.32±0.71) and Causal Attribution (2.13±0.18).

Mothers did perceive that caring for a child with mental retardation had a positive effect on family life. In the Positive Contribution sub-scale, the higher scores were observed for learning through experience with special problems in life, happiness and fulfilment, strength and family closeness, understanding life's purpose, awareness about future issues and personal growth and maturity. When comparing their situation with others, similar mean scores were observed for downward comparison with others (3.29±0.51) and an upward favourable comparison (3.13±0.07). In the Causal Attributions sub-scale, the highest means were observed for perceiving that the disability is associated with fate or chance (3.12±0.41) or that there is a special/higher purpose (3.08±0.98). Mothers' perceptions of being able to influence outcomes

was part of the Mastery Control sub-scale, where personal sense of control was (2.26±0.40) perceived to be higher than the professional sense of control (2.00±0.49).

Discussion

The present study showed, in agreement with other studies from Pakistan, that there was a perception of acceptance of disability as a result of fate and a sense of stigma and self blame.^{4,5} However, the study was also able to report that caring for a child with mental retardation does make positive contributions to family life.¹¹ The perception of happiness and fulfilment provide further insights into caring for a child with mental retardation in a developing country setting where protective factors are seldom reported. The sense of personal growth reported here has also been shown in a previous qualitative study among mothers living in a low-income community in Karachi,⁵ which may be an opportunity for service development such as peer-to-peer counselling, parenting programmes or awareness generation. In general, mothers compared themselves favourably with other parents who had children with mental retardation. It is imperative to realise the importance of support within and outside the family, especially from ones who have a child with similar challenges. It is only a parent of a disabled child who can grasp the feelings, heartache, guilt, fear and responsibilities that parents with a similar child experience.¹²

The positive perceptions, favourable social comparisons and perception of control are not dimensions of caregiving for children with disabilities that have been reported in the Pakistan context where the focus has been largely to examine the negative contributions. This is not to suggest that families do not experience stress or face substantial challenges in seeking out basic information and services for their children, but to acknowledge that going hand in hand are positive experiences which may contribute to building resilience in families. In developing future models for support, strategies where families are encouraged to share a complete experience may facilitate in identifying positive coping strategies.⁸

In Karachi, there are only a few special education services, while developmental and rehabilitation services are scattered and often difficult to access for many families. However, with growing awareness and media attention, parent groups through clinical and education centres are growing and opportunities to develop these should be capitalised upon. More research exploring family coping strategies are needed in developing countries where the level of external support is likely to remain limited in the near future, and where low-cost support interventions at

family and community levels, such as peer counselling, may be a feasible way forward.

Conclusion

By providing better access to parents providing care for disabled children, the potential of utilising the positive experiences and perceptions of families dealing with the challenge can be channelled for individual and social betterment.

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