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RESEARCH ARTICLE

PARENTAL CONCERNS QUESSIONAIRE BASED STUDY TO EVALUATE PARENTAL EXPERIENCE FOR CARING OF CHILD WITH AUTISM

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ABSTRACT

Background: Caring for children with autism spectrum disorders (ASDs) is challenging and affects family life.
Aim: To explore the adaptive behaviors and beliefs of parents toward their child with autism.
Material and Method: Parental Concerns Questionnaire (PCQ), a scale composed of 20 items relating to core and behavioral symptoms of autism were used. The answers were in the form of 'yes' or 'no'.
Result: Findings revealed that parents who have a child with autism experienced multiple challenges in different aspects of care, impacting on parents' stress and adaptation.
Conclusion: Parents physical and psychological well-being was observed to be affected, both positively and negatively, while raising a child with autism in the childhood period.

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INTRODUCTION

Autism spectrum disorders represent a specific pattern of abnormal development defined by three core symptoms: impairments in reciprocal social interaction, deficits in verbal and nonverbal communication, and a restrictive and repetitive repertoire of activities and interests (Desai, 2012). Caring for children with autism spectrum disorders (ASDs) is challenging and affects family life (McConkey, 2009). The prevalence of autism has been on the rise is in part due to an increase in awareness and health service provision, as well as improvements in diagnostic practices, leading to earlier detection and diagnosis of children with autism (Blumberg, 2013 and Charman, 2002). Autism typically appear during the early years of childhood, when parents realize that their child does not respond to communication or does not show any affection or speak. These symptoms spark concern in parents, prompting them to seek professional help or opinion, leading to a diagnosis of autism (Zeedyk, 2014). Moreover, in general health of these children is lower than that of typically developing children. Upon receiving the diagnosis, parents are faced with the loss of expectations for a typically developing child and are faced with uncertainties regarding not only the child's but also the family's future (Dale, 2006 and Poslawsky, 2013).

Meeting the high care demands of affected children requires much time, effort and patience. This often results in psychological distress, depression, anxiety and other mental or physical health problems among their parents (Bromley, 2004; Hamlyn-Wright, 2007 and Khanna, 2011). Moreover, many parents face financial problems (Kuhlthau, 2010a). Children with autism often do present families with considerable challenges requiring external support (Daley, 2004; Gupta, 2005; Kishore, 2011). Parental perceptions of intellectual disabilities has also noted diverse frames of reference featuring sociocultural, spiritual, and biomedical components (Edwardraj, 2010). This study was done to provide and explore the adaptive behaviors and beliefs of parents toward their child with autism, their family, and social experiences, as well as parents' perceptions toward health and educational services.

MATERIALS AND METHODS

The current study focused on parents' experiences of and with their child from birth to the present time. Primary inclusion criteria were parents with a child who was already identified as meeting criteria for ASD. To fill this need, we developed the Parental Concerns Questionnaire (PCQ), a scale composed of 20 items relating to core and behavioral symptoms of autism. The answers were in the form of 'yes' or 'no'. The data was analysed in the form of percentage. This study examines the reliability and validity of the PCQ. Our sample consisted of 50 children with a clinical diagnosis of autism spectrum disorder or typically developing children between 4 and 10 years of age recruited for a study of sleep and behaviour in children with ASD.

- Response of parents upon receiving the diagnosis of autism was negative.
- Do you initially deny the diagnosis?
- Do you blame yourself or felt guilty for the condition of your child?
- Does parenting a child with autism impacted your daily life?
- Does caring for the child's health leads to financial strains, inaccessibility or insufficiency of financial support?
- Does caring leads to health issues in parents?
- Did the coping strategy help improve the child's health?
- Does emotional relationship help to cope with the situation?
- Are you confident enough for your child's future?
- Was denial common in reactions from extended family?
- Having a child with autism resulted in strained marriage.
- Was it difficult to perform typical family activities?
- Did the support groups meet your needs?
- Did sharing problems with other parents helped?
- Was going out in public perceived to be difficult?
- Is isolation a common experience in such case?
- Did use of special diet or supplements improve health of your child?
- Was the experience with health care services good for them?
- Did interaction with health care professionals preserved their sense of hope?
- Were you satisfied with your child's inclusion in school?

DISCUSSION

The challenges of caring for a child with autism is a worldwide context. Parents' fundamental concerns throughout their journey were: learning to meet new and unfamiliar challenges as parents, caring for their child's basic needs, and finding an engaging niche with a sense of belonging for their child in the everyday milieu. Both culture-specific and potentially universal levels of experience are delineated in the overall findings (Khanna, 2011). Parents' experiences of their child diagnosed with ASD were found to be intimately tied in with fundamental human concerns: that a child is cared for, belongs in the social world, engages in practical activities, and finds enjoyment and contentment in life. These findings imply that helping families meet these needs locally can go a long way towards supporting parents and children in their life journeys (Gupta, 2005 and Kishore, 2011). In this study we observed that maximum parents denied the diagnosis and were not ready to accept the condition. Parenting a child with autism caused financial as well as health issues which impacted their daily life. Parents felt that coping strategies like reading books and emotional support help with the development of child. Majority of parents were not confident about the future of their child, which worried them a lot. Most of the parents were not able to perform daily activities, even they were not accepted in families and this caused stress in their married life. Public stigma was common which caused isolation in their life. Support groups and sharing their problems were helpful in dealing with their child. Special diets were not useful in such conditions. Helath care systems were helpful but, parents required more support and knowledge from such healthcare professionals for easy understanding of the disorder and caring of their child. Minority of the parents were satisfied with their children inclusion in school. The present study has several limitations. The sample was limited to parents who have had contact with professional care centers and whose child attended various services regularly. Families who never made contact with professionals were not included; the sample thus offered a picture of only a limited segment of local

RESULTS

The data of the questionnaire was analysed in the form of 'yes' or 'no'. It was calculated in percentage.

Sr. no	Question	Answer(%)	
		Yes	No
1	Response of parents upon receiving the diagnosis of autism was negative	78	22
2	Do you initially deny the diagnosis	67	33
3	Do you blame yourself or felt guilty for the condition of your child	58	42
4	Does parenting a child with autism impacted your daily life	51	49
5	Does caring for the child's health leads to financial strains, inaccessibility or insufficiency of financial support	77	23
6	Does caring leads to health issues in parents	57	43
7	Did the coping strategy help improve the child's health	69	31
8	Does emotional relationship help to cope with the situation	73	27
9	Are you confident enough for your child's future	34	68
10	Was denial common in reactions from extended family	71	29
11	Having a child with autism resulted in strained marriage	55	45
12	Was it difficult to perform typical family activities	67	33
13	Did the support groups meet your needs	69	31
14	Did sharing problems with other parents helped	70	30
15	Was going out in public perceived to be difficult	67	33
16	Is isolation a common experience in such case	82	18
17	Did use of special diet or supplements improve health of your child	38	62
18	Was the experience with health care services good for them	57	43
19	Did interaction with health care professionals preserved their sense of hope	59	41
20	Were you satisfied with your child's inclusion in school	39	61

experiences. Also, the study relied on interviews with parents, whereas direct observations of family life were not systematically conducted. Consequently, the current study could not do full justice to the complex everyday experiences of families. The present study revealed similarities to other areas in India; however, more research from other regions in this vastly diverse country would be needed to further confirm and extend the conclusions of this paper.[16] Further research is particularly needed for examining instances of parents and professionals fruitfully collaborating on the paradox of child acceptance–social acceptance/child change–social change.

Conclusion

The provision of timely, adequate, and continuous support to parents is important in empowering parents to adapt to the lifetime diagnosis of autism, which can be addressed by improvements in public awareness, policy making, and health care practices. Such improvements should involve recognizing parents as experts of their child, an important aspect observed to be lacking among health care professionals and the public alike. Health care provision should be family centered, addressing and supporting the needs of the whole family and not just the affected child, to ensure the family's well-being and quality of life in the face of a diagnosis of autism.

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