

Negotiating Future Uncertainty: Concerns of Mothers of Children with Down Syndrome in Kashmir, India

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ABSTRACT

Purpose: Down syndrome is developmental disorder that poses unique challenges and implications to families. The present paper is the outcome of a study carried out in Srinagar district of J & K in India, on mothers' apprehensions about the uncertain future for their children with Down syndrome.

Method: A phenomenographic approach was followed. Purposive sampling technique was used at selected special schools in Srinagar. Mothers of 8 children with Down syndrome who were enrolled in school, participated in the study. The mothers were between 31 and 67 years of age; their children were between 2 and 30 years of age. In-depth interviews were conducted in Urdu and Kashmiri, the local languages. The recorded information was subsequently transcribed and classified into themes.

Results: The key theme that emerged was the participants' worry about the unpredictable future of their child. Once a child is diagnosed with Down syndrome, parents - especially mothers - recognise that their child's future may not include a carefree childhood and, at a later date, higher studies, an independent life and marriage.

Conclusion: Mothers of children with Down syndrome experience high levels of stress and often have to make adjustments in their careers, finances and lifestyles. There is a need for training programmes to help parents cope with the problems faced by their children with Down syndrome. Stakeholders in the education sector could help in this regard.

Key words: Down syndrome, mothers, special school, future, Kashmir.

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INTRODUCTION

Every family of a child with Down syndrome experiences a unique set of stressors according to their child's age, functionality and developmental stage. Down syndrome is one of the most common genetic disorders, with reports of one infant in every 600-800 live births (Alton, 1998). Down syndrome is predetermined before conception. It is caused by the fertilised egg having three copies of Chromosome 21 instead of the normal two (Davis, 2008). It is considered to be one of the easiest neurodevelopmental genetic disorders to detect because of the physical and mental abnormality and genetic testing. There are also prominent neurocognitive deficits associated with Down syndrome such as communication, language, and memory impairments. Many families in today's society almost idolise their children, as children carry their parents' hopes and dreams. Donahoo (2007) noted, "Of course, creating the perfect child or perfect childhood is impossible, but that has not stopped us from expending tremendous amounts of energy trying". He described the phenomenon as arising from social and economic factors, such as more money and more competition, to the point where children have become the latest status symbol for some parents. Within this context, life with a child with disabilities gives parents unique experiences, with unique joys and difficulties. Previous studies have revealed that mothers of children with Down syndrome face a variety of challenges throughout their children's lives (Baum et al, 2008). They might experience emotions such as grief, depression, guilt and self-blame (Myers et al, 2009). The burden of caring for children with Down syndrome has been reported to contribute to maternal stress, and the parental function can be affected due to stress and pessimism about the future. While it cannot be disputed that the arrival of a child with a disability results in some distress for most family members, it may be argued that families also have the capacity to make the necessary adjustments and accommodations which are necessary to keep the family functional (Gallimore et al, 1993). There is emerging evidence that following an initial period of shock after the arrival of a child with Down syndrome, many families show evidence of coping during the subsequent stages of early and middle childhood (Mahoney et al, 1992). In fact, almost three decades ago, Hewett (1970) noted that following this initial period, many families make a remarkable adjustment to this situation and show extraordinary levels of resilience. This suggests that it may in fact be the presence of disability and the need to address the related demanding issues which results in the heightened resilience that many families experience (Bower, 1996). Bower et al (1998) found

in their research that the presence of a child with Down syndrome can no longer be seen as a universal catalyst for family difficulties or family dysfunction. They suggested that the ideas and beliefs of family members, including the extended family, need to be understood in order to appreciate how families cope with the challenges of parenting a child with a disability. However, a family may also require different levels of support to manage the demands required by specific health, behavioural and education needs of their child, of which they have little knowledge or experience.

Caring for a child with Down syndrome can be challenging and demanding. Families face unprecedented social and financial difficulties that are not well understood or evaluated by professionals. Previous studies reveal that mothers of children with Down syndrome face a variety of challenges (Gatford, 2001; Cuskelly et al, 2009; Chan et al, 2014).

Despite the incidence of Down syndrome in Kashmir, there is a dearth of research on the experience of local families, especially of the primary caregiver (mother) of a child with Down syndrome. Additionally, the effect on the caregiver's life is not clear. Accordingly, this study focusses on exploring and mapping the qualitatively different experiences of mothers caring for a child with Down syndrome within the broader context of disability in Kashmiri society.

METHOD

Approach

This research employed a phenomenographic approach (Marton, 1981, 1986; Marton & Booth, 1997) to identify the qualitatively different ways in which mothers experienced the phenomenon of parenting a child with Down syndrome. While any phenomenon encountered by an individual may be infinitely complex, there are also a limited number of critical features that characterise any phenomenon. Phenomenography is a qualitative research method, used since the mid to late 1970s, that seeks to identify these key aspects in how individuals perceive, conceptualise and understand a particular experience (Marton, 1986). While the current study involved only a small sample, it provides an important example of how phenomenographic research can be used to study the experiences of families with special circumstances to identify the commonalities and variations in their experiences.

Study Sample

The mothers of children with Down syndrome were selected using purposive sampling technique from the selected special schools at Srinagar, in Jammu and Kashmir. The researchers contacted the school authorities to inform mothers of children with Down syndrome about the date of interview. The interview was conducted during their next visit to the special school. At the first interview the researchers obtained participants' informed consent and permission to tape-record the conversation.

Only 8 children with Down syndrome were enrolled in the schools and all the 8 mothers of these children agreed to participate in the study. Participants ranged in age from 37 - 61 years, and the children's ages ranged from 2 - 30 years.

Table 1: Participants' Background Information

		Number of Participants (N=8)	Age Range (Years)	Locality
Biological Mothers	Females	8	37-61 years	Urban

Data Collection

In-depth interviews were conducted in privacy, in a selected room in the special school, in Urdu and Kashmiri, the local languages. The purpose of the research study was explained and the interviews started with open-ended clarifying questions like, *"Would you share with me your responses when you heard that your child has Down syndrome?"*. The initial interview at the special school was followed by home visits. Each interview lasted for 40 - 70 minutes. The interview records were transcribed later on.

Data Analysis

Phenomenographic analysis is a holistic process. The critical features of the phenomenon (or phenomena) under investigation are represented as categories of description (Ryan, 2000; Åkerlind, 2002). The set of categories of description cannot be known in advance but emerge from the data. The categories of description represent the range of qualitatively different ways of experiencing the phenomenon in question.

RESULTS and DISCUSSION

A hierarchical thematic framework was developed and used to classify and organise data according to a key theme. The key theme that emerged from the narratives of research participants was the worry about the unpredictable future of the child. Furthermore, the theme is categorised into three sub-themes: School Placement, Work and Independent Living and Marital Life

Sub-theme 1: Worried about the Unpredictable Future of the Child (School Placement)

After diagnosis and realising the problems they faced, all the 8 participating mothers were confronted with the task of adapting to the positive and negative impacts of having a child with Down syndrome in the family. This theme captures the unpredictable future experiences and attitudes of the mothers “living with Down syndrome” and describes the perceived toll taken on their well-being.

The immediate challenge that mothers encountered was the child’s school placement after attaining the age of 3-4 years. Their concerns about their child being in school were: their child’s behaviour with other students and the teachers; and, how he/ she would be treated in the absence of the mother. Furthermore, mothers felt uneasy about the child’s self-caring ability, and the ability to earn a living and become independent. Looking ahead to the future, most of the respondents were worried about whether their child would be able to take care of himself or herself in later years.

“She worries whether her child will be able to go to school, behave normally with other mates in the school, and make friends” (M1, mother of a 3- year-old son).

“I am not interested in sending him to special needs school; I think he should not be separated from others” (M2, M8).

The proximate worry that mothers had was about the education system for their child with Down syndrome.

“I can’t send my child to school where normal children who are physically and mentally fit are admitted. Every school within the valley has its own criteria for admitting a new child in their schools. So far my child is concerned she doesn’t fall within the prescribed criteria of selection. This is the thing which hurts me like anything” (M3, mother of a 4-year-old daughter).

“My child with Down syndrome is not accepted in every school except for special schools” (M4, mother of a 3-year-old son).

Parents’ concern about whether their child would ever be able to achieve independence was based on their perceptions of their child’s poor education.

“I am anxious as he cannot speak and learn properly, but it is important to be educated for endurance in the society” (M5, M2, M8).

Rimmerman and Duvdevani (1996) in their study found that the age of a child with intellectual disability has also been found to predict parental stress levels. A family may experience greater stress when their child with intellectual disability enters school and parents become more aware of the achievement differences between their child and same-age classmates. Wikler et al (1981) in their study revealed that when the child enters school, more time and effort is needed on the part of the parent to help the child be successful. Additionally, as children get older, parents may not have access to information on how to cope with older children with intellectual disability.

Sub-theme 2: Worried about the Unpredictable Future of the Child (Work and Independent Living)

Another concern that mothers had was regarding their child’s ability to work and live independently once the child was older. Mothers felt uneasy about their child’s future.

“My son cannot walk properly; I doubt what his ability would be, what level of support would be required for him to walk” (M5, mother of a 3- year-old son).

Parents were worried that their child’s developmental delay would make it difficult for the child to get a job and become financially independent.

“The doctors told me that his mental development will be slow, he may not be able to learn properly like typical children do, it is difficult for him to get a job and live independently” (M1).

The stress factor that mothers discussed referred to the options available to their child once the child had joined school. Some mothers were concerned about their child’s ability to be independent and make complex decisions such as taking the bus or talking to strangers.

“The big stressor is her vulnerability to be able to solve problems and make important

decisions on her own; things like catching the bus and dealing with the people that are not known to her” (M6, M1).

On the other hand, mothers who had made plans for their child's future, or were aware of transition and employment, were concerned about another aspect.

“My main concern is what will happen to him when I’m not around anymore, will he be able to cope in society, live independently and make a living” (M7, M3).

The major long-term stressors that mothers expressed were their fears about who would take over care of the child in the event of their death. Mothers were also concerned about planning ahead to ensure their child's future happiness and independence.

“All love and care will be given to my child till he lives with me but the thing that I am most worried about is if I die before my child dies who will take care of him and will he be able to live independently” (M8, M4).

“I am concerned about her future when I won't be around anymore” (M1, M7, M8, M5).

“I wish and pray to God that I live long enough and can take care of her till she is alive” (M7, M8, M1, M2).

“All the love and care will be given to child till they demand it but nobody knows about the life and death, who will die and when” (M3, M6, M4).

The Bureau of Labour Statistics (2010) reported that only 19.2 % of persons with disabilities were employed. Eight out of ten persons with a disability are not in the workforce at all. There is a wide variability in life outcomes for persons with Down syndrome. The new possibilities are not yet the norm, with much work still to be done. While a young mother worries and tries to prepare for her child's future, life goes on with a young child with Down syndrome and shapes the family.

Sub-theme 3: Worried about the Unpredictable Future of the Child (Marital Life)

Almost all the mothers shared similar concerns about their child's long-term future and reduced life expectancy; that they would not be able to complete higher studies, get married, have children and live a happy life. Mothers were very unhappy at the thought that their children would not be able to experience significant events and lead a happy life like normal families.

"Because of her limited life experiences neither she would go to college nor she will get married" (M5).

"Dream of becoming grandmother has shattered forever, as he cannot marry and have children" (M1).

"I don't know whether he will marry and have children" (M4, M8, M5).

"I know he cannot become a father and I won't be able to become a grandmother" (M3, M7, M1, M8).

"I don't know what will happen to her in future, I believe in written destination" (M3, M5, M8).

Some of the parents hoped that their child would find some means of earning a living and lead a normal life by getting married.

"I hope that he will learn some skills so that he may work to help him live his marital life and have children" (M2).

"Unlike normal children my child is having intellectual disability; it is quite clear that he cannot live independently nor can he marry" (M4).

A qualitative study was conducted by Graungaard and Skov (2007) on parents' experiences, coping and needs, when their newborn child had severe disability. Results showed the certainty of the diagnosis was central to parents' experiences. First, the emotional reactions of the parents were highly influenced by the diagnostic process, and secondly they found difficulty in coping with an uncertain future. It can be a very difficult and trying time for families who have just found out that their baby has Down syndrome. They would have many questions, concerns and fears about the future, so adequate support groups and other help-lines should be provided for families of children with disability.

CONCLUSION

The aim of the study was to explore the experiences of mothers who are raising children with Down syndrome and how they have adjusted in different areas of family life following a diagnosis.

There are a lot of challenges for parents in bringing up their children with Down syndrome. Parents have to spend a lot of time in order to meet the needs of these children and tend to neglect the other children in their family. Participants

became anxious and worried when their children did not develop speech, and when behavioural problems became difficult to manage. The findings that emerged from this study were that mothers of children with Down syndrome experienced high levels of stress and often had to make adjustments that affected their careers, finances and lifestyles.

It was found that the school-based clinic was another route for children with Down syndrome to receive primary healthcare as well as physical and behavioural healthcare using multidisciplinary teams of nurses, practitioners, doctors, psychologists and social workers.

There is a need for training programmes to help parents to cope with the problems that their children with Down syndrome face. Stakeholders in the education sector should devise a wide range of programmes aimed at meeting the needs of these parents.

The concerns revealed by most of the parents in this study support the common perception that people with intellectual disability and their families experience burdensome lives. Feelings of sadness were reported by mothers caring for children with Down syndrome; they were generally worried about their child's future, including aspects of study, employment and marital life in the future. They also explained the differences between their own situation with their child as compared to other children with Down syndrome, and also with families who led a normal life.

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