

Exploring Support System for Parents of Children with Disability: Role of Religion

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Abstract

Life is the most important gift from God. Everything becomes beautiful when an individual is health both physically and mentally. For an economically sound individual, dealing with any health problems is to some extent easy when it comes to negotiating with the health related expenditures, but for an individual who is economically weak, illness appears difficult and stressful and almost impossible to manage especially if the health problem is severe and not curable like Down syndrome. In such situations people often resort to seek help from the religion. In case of Muslims, the belief is that whatever Allah bestows upon them is best for them. Among Muslims having children with Down syndrome is considered a curse for the parents, while in some other societies it is considered reward from God. So the perceptions vary while interpreting the phenomenon of Down syndrome. Despite different interpretations, the socio-economic burden of the disease remains the same. The present paper focuses on those parents whose children are suffering from Down syndrome and are working in unorganised/ informal sector as workers in this sector generally lack any public funded social security support, therefore have low economic status. The research has been carried out not only to study socio-economic problems of parents with children having Down syndrome but also to study the various coping strategies parents adopt in order to deal with the problem. So far the present research is concerned; it has been carried out in district Srinagar. Qualitative method has been used in order to gather the data.

Key words: Down syndrome, Religion, Support, Kashmir

Introduction

When a mother gives birth to a child in family with a disability, the unforeseen and permanent nature of such a case generally increases a parent's exposure to different stressors and can present parents with many challenges that may not be centred on their child's disability, but on the impact of the disability on family functioning, acceptance, adjustment and quality of life. There is a significant evidence to indicate that parents of children with developmental disabilities (DD) experience greater stress compared to the parents of children without Developmental Disabilities^{1,2} (Konstantareas, 1991; Scorgie, Wilgosh

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& McDonald, 1998). Historically, from the research it has been assumed that outcomes for parents of children with Developmental disabilities may experience additional stressors such as the demands and service that are not fulfilled and financial problems that would inevitably lead to pathology and dysfunction^{3,4} (Byrne & Cunningham, 1985, Dykens, 2000).

Down syndrome is the most common genetically caused intellectual disability^{5, 6} (Patterson & Costa, 2005; Sherman, Allen, Bean, & Freeman, 2007) characterized by a range of physical abnormalities and developmental delays in motor planning skills, language, and cognitive skills. In addition, it results in a relatively high risk for a number of conditions as it can be associated with congenital defects of the heart, gastrointestinal tract, eyes, and other organs. Throughout the lifespan, persons with Down-syndrome manifest higher risks for specific endocrinological (especially hypothyroidism), infectious, dermatologic, oral health, cardiac, musculoskeletal and other organ system disorders⁷ (Murdoch et. al, 1977). Medical conditions and birth defects may lead to an increase in hospital visits, surgeries and financial stress, which in turn can adversely affect the psychological well being of family members especially the parents. Indeed, parents of children diagnosed with developmental disabilities may feel 'stunned, numb, sad, shock and regret when first learning of their child's diagnosis'⁸ (Teti, o'connell, & Reiner, 1996, p.240). Moreover, they exhibit high rates of disorders of the special senses of vision and hearing⁹ (Roizen et al, 1993). Despite the widespread use of prenatal screening for Down syndrome, the incidence of Down syndrome remains steady; occurring once in every 700– 1,000 live births (Mikkelsen, M, 1981) and the rate is reported to have increased by 31.1% since 1979¹⁰. Many factors including late marriage have been associated with the increase in the prevalence of Down syndrome. The trend of late marriages in Kashmir for the past 20 years or so is taking a heavy toll on the children of these couples, including genetic disorders like the Down's Syndrome, different genetic disorders were found among the Kashmiri population "possibly due to late marriages with maternal age of the patients higher." "Down's syndrome seems to be occurring at a higher frequency in those persons. The research carried out between 2004 and 2011 had evaluated 773 suspected cases for different genetic abnormalities from different regions of Kashmir. "Out of 773 patients, abnormal chromosomes were found in 127 (17 percent) of the cases," It revealed, out of 100 suspected cases, Down's Syndrome was found in 82 (28 percent) cases, Turner's syndrome in 39 (20 percent) of 200 suspected cases, Klinefelter's syndrome in 4 (3 percent) of 140 suspected cases and 2 (1.5 percent) cases with translocations in chromosomes observed in 133 suspected cases of women who had one or more missed abortions. "Among Down's syndrome it was found that 39 of 82 (47.5 percent) were females and 43 of 82 (52.5 percent) were males. Down's syndrome cases belonged to the mothers

with middle age of the conception (maternal age >35) with occurrence in 61 of 82 (around 75 percent). “In Turner’s syndrome, 7 of 39 (18 percent) cases were found to be with mosaic chromosomes and most of the cases showed abnormal anatomical features the reproductive organs especially Uterus and Ovaries¹¹ (Farhat A. Shawl, 2013). The researcher 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, behavioral and education needs of their child for whom they have little knowledge or experience. The main aim of this research paper is to investigate the role of religious beliefs in the lives of parents having children with developmental disability, specifically Down syndrome. In particular the role of faith, prayer, fasting, spirituality and religion in minimising or overcoming the stressors linked to parents having a child with Down syndrome or intellectual disability is explored. Spirituality and religion were considered as individual concepts in terms of their role in facilitating acceptance, coping and providing a support system to parents of children with Down syndrome or intellectual disabilities

Method

In-depth interviews were carried out in Urdu and Local language Kashmiri. Participants were selected on the basis of purposive sampling. The researcher purposively selected special schools in which children with Down syndrome are enrolled. The list of parents of these children was collected from special school providing schooling, speech therapy, physiotherapy and medical and psychological assessment for children and young adults with intellectual disabilities. The study included a sample of six (06) fathers of children with Down syndrome. All the participants were Muslims. They ranged in educational attainment from no qualifications to master’s degree and, in household income, from unemployed and dependent on charity to affluent and owning their own business. Participants’ age ranged from 37 to 61 years, and the ages of their children ranged from 2 to 30 years. All the parents in this study were given a diagnosis of Down syndrome after their child was born. An interview guide was devised to explore participants’ experiences of the social, emotional and financial implications of having a child with Down syndrome and their advice on termination of pregnancy to prospective parents receiving a prenatal diagnosis of Down syndrome. All participants were provided with information about the study, and written consent to participate was obtained. Interviews were conducted by the researchers in Urdu or Kashmiri at their

respective homes (Home visits). Interviews were carried out separately with all the participants, and mothers and fathers of the same child were also interviewed separately. Each interview lasted between 30 and 50 minutes, were audio recorded, translated and transcribed. Some participants became upset during the interviews, at which point consent to continue was obtained. The authors assured the quality of the translation and transcriptions by listening to audio-recorded interviews and conducting the analysis simultaneously. The limitation of the study is that most of the respondents were busy in taking care of their children that is why only three families participated in the study.

Data Analysis

Phenomenographic analysis is a holistic process. The critical features of the phenomenon (or phenomena) under investigation are represented as categories of description (Akerlind, 2002; Ryan, 2000)^{12, 13}. 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

From the date interview there emerged a diverse nature of experience in parenting a child with Down syndrome. The results that emerged from the in-depth interviews were identified according to the following theme:

Religion and spirituality as a support system

The parents highlighted that the most effective support to coping with difficulties and stressful periods was their own personal spiritual beliefs and thought processes. Other avenues of support that they found beneficial in facilitating coping were religious beliefs, personal beliefs and prayer.

In regards to the influence of personal religious values on the process of coping with stress, there are two distinct ways in which religious values have been found to help reduce stress. Firstly, religious values give the impression of helping people change their perception of the world. It appears that having a strong, deeply-rooted system of religious beliefs is able to change people's overall sensitivity to a stressful situation or life circumstance. As such, people are more easily able to escape some of the threat and fear that such situations would otherwise evoke, and also find a deeper meaning for their circumstance¹⁴ (Grzymala-Moszczyńska, & Beti-Hallahmi, 1996). Religion also appears to have superficial influence in regards to helping people cope with stress as it provides behaviours which help people to cope with their negative emotions.

Some of these behaviours include prayer, reading the Quran and attendance of religious services. It also seems that people who possess internalized religious values appeal more readily to religion as a helpful means of coping with stress and that the more intense these religious values, and the greater the stress experienced, the more they will rely on religion as a resource ¹⁵ (Shumaker, 1992).

Spirituality is conceptualised as both the religious and personal beliefs held by an individual ¹⁶(Fewell, 1986). Although clearly linked spirituality and religion should be viewed as conceptually distinct constructs. Individuals do not necessarily have to be followers of a specific religion to consider themselves spiritual ¹⁷(Canda, 1999). Both aspects of spirituality defined in the methodology may potentially influence the coping of fathers of children with Down syndrome.

The fathers found that they turned to spirituality when they were going through tough time in their life, particularly when they were receiving diagnosis of their child with Down syndrome as they could see no hope.

Each father experienced and reflected upon the spiritual dimension of his life differently. The fathers who had a religious background used those religious beliefs and values as coping mechanism. Other fathers had a more self-reliant approach, using their own experiences and beliefs to help them through life's adversities. Of the six fathers interviewed, four fathers used a more personal belief approach while two had a formal religious approach to coping. Having a child with Down syndrome challenged each father's spirituality. The challenges had the effect of either reaffirming or weakening religious beliefs.

"I have belief that there is a god who is the best of planner of everything, of which we don't have even thought off. We don't have any knowledge. God has put me on a trial and I believe that God likes to put his loved ones on trial in order to check whether my slave will remember me in times of trouble. I have full faith on god that everything will be ok in future. Having a child with Down syndrome is trial from god and I know god will take me out of this trial." (F2)

"Though my thinking has changed a lot due to facing my child's problem from a long period of time, this problem has even affected my perception towards god. I used to pray god in past for the well being of my child for hours together but now I still pray to god by giving more time in worship of god as compared to past" (F3)

Fathers found themselves perplexed with their personal religious beliefs. They were inquisitive about the presence of a God who let them suffer and experience the feelings that everything is wrong and nothing will turn out well

despair. Many fathers experienced anger towards God by putting them and their children in the state of distress and suffering.

"I still have faith on God but sometimes i question myself if God is supreme and most powerful then why people experience difficulties in life?. This reaction sometimes creates frustration within me, showing anger towards God" (F2)

"My faith (eemaan) about the God is that if he is the well wisher of entire human kind, then why God brings trouble in our life by blessing us with a child who is not physically and mentally fit" (F4)

Others, whose faith was reaffirmed by the birth of their child with Down syndrome had also experienced this anger, but described it as part of the process of coping. They reflected that it was easier to be angry with God than the people who were trying to support them. They found that the anger was temporary and was usually during the initial diagnosis period. They found that when they had overcome that anger and achieved a shift in their perception of the world they were able to use their religious beliefs to cope with the difficulties of having a child with Down syndrome.

"Initially when my child was diagnosed with Down syndrome i felt that i was discriminated by God by bestowing me a child with disability, I showed some anger towards God and i used to curse myself but as the time passed i realized that God can never do injustice to mankind. I still keep on praying to God with this belief that one day God will solve all my problems" (F4)

"i believe that the child i am bestowed with Down syndrome may be because of some bad deeds i may have committed in past and the way we are supposed to follow the path of God we don't follow it that way because God doesn't like those activities which are not acceptable before him. But i live up with this hope that God is the most merciful and the most forgiving and has not left us alone to cope with these things on our own" (F1)

"i don't blame God for all that has happened to my child because it made me learn the difference between God and life . We expect bad things to happen in this sinful world we are living, but we cannot blame God because he has given us power of making free choices"

(F5)

The parents used religious beliefs predominantly during the birth/diagnosis period or during times of high emotional stress such as when a child was having severe medical conditions requiring a surgical procedure. Fathers

disclosed that it gave them hope and comfort knowing that they were not alone. The belief in a higher power gave some fathers a feeling of control and fix firmly and stably during the troublesome problems and unpredictable situations, making them feel more emotionally secure. Religious beliefs were also found to facilitate and shape acceptance.

“God is not indifferent to its people, he is wise and loving, it was part of Gods plan but this should not make us fatalists, everything is going to be fine” (F3)

“I think what when a misfortune happens that is when i probably want to try and come closer to God and feel relaxed. I realize that God alone controls everything, so i trust and rely on him, God doesn’t burden any human being with more than he is well able to bear” (F4)

“I feel no one is there to help me in difficult times and i think i am no longer able to cope but it can be helpful for those who are suffering to recall that God is always there and assist those who place their trust in him” (F1)

Prayer

“I feel relieved all the time when i see her health conditions improving, so i feel hopeful all the time” (F2)

“It gives me a sigh of relief, She has improved a lot, started walking on her own. It is proud moment for us” (F4)

Fathers found prayer to be a valuable avenue of support in assisting them during difficult situations. They found that it facilitated coping and was a means of communicating with God.

Many Fathers highlighted that prayer helped them relax and provided comfort during stressful occasions such as when a child required surgical intervention. Fathers also found that prayer gave them the strength to deal with difficult situations. Prayer was used frequently when Fathers felt isolated, anxious or depressed. Fathers found prayer to be a strong means of coping during a crisis.

“My Childs problem was becoming a day to day challenge for me, as i was trying to get out of this; more i was found myself with this problem. But i prayed to god to help me. I thought that this is the will of god and god might have planned something good for me, even having this problem. This positive thinking helped me a lot while dealing with my Childs problem. I thought that being in tension and thinking so much about this problem will not help me any way. The best way is to deal with this problem by taking the name of god and by praying to god to do shower of mercy not only up on me but also on those parents who are facing similar type of problem” (F1)

"I kept on praying to god to improve my child's condition that is going through tough time (undergoing surgery). I was really crying like anything. Praying gave me some sort of relief that everything will be fine" (F3)

Personal beliefs

Generally the majority of the fathers who used their own personal beliefs, behaviours, values and framework for living found that these beliefs were strengthened through having a child with Down syndrome. Fathers found that they became less reliant on faith and more dependent on their own thought processes and logic to assist them in coping and acceptance. Fathers who relied more on their internal thoughts, dealt with the problems positively rather than digging deep in to negatives.

"It is really futile to think about the past. I have more than enough to handle dealing with this problem. God has given me the brain to think positively" (F3)

"I have grown stronger with the passage of time in dealing with child's problem. I find strength to carry on and endure in spite of overwhelming obstacles. I think it certainly helped me"(F6)

Social support

Fathers disclosed that their friends and relatives were the ones who supported them spiritually who had similar experiences in life, strengthened their emotional support system. Fathers also disclosed that they mostly relied on themselves for spiritual support, using their own beliefs and gave description for living to guide decision making.

"When i was in great fix and was not getting what to do, at that time after god my friends came for my support. They encouraged me a lot and counselled me time to time" (F3)

"I being a parent was very much concerned with the problem of my child and in order to deal with this problem the best source of emotional support was my wife and my relatives. My wife always used to tell me that everything will be fine as it used to be before" (F2)

Hope is an attribute of spirituality that assisted with coping. It is a process of believing in a positive outcome related to stressors or difficult life events. Fathers described that through the process of hope they were able to gain a sense of control, adaptation and direction. Hope was also gained through the positive attitude of the child as all the children were content with life despite any struggles they may have experienced.

Conclusion

Life is a beautiful thing from god and everyone in this world is trying to make their life beautiful by praying to god. People belonging to any religion believe that god is always there to help; same is the case with people belonging to Muslim community. Muslims like other religious community believe that god is there who is the creator and sustainer of the entire universe. The core idea of Muslim faith is that god is the best planner and whatever god plans is best for his slaves. The research revealed that religion has an important place in the life of respondents concerned. Parents use religion as a tool in order to tackle problems encountered in life. Parents revealed that their child problem has brought us more close to god. Further it was revealed that apart from religion in order to deal with their child problems, father use spirituality and hope as a tool to deal with the problem and fathers get this social support from their relatives and friends. The research revealed that religion has a central place in the life of people, especially the respondents concerned, from religion they are trying to get relief.

Acknowledgement:

The authors would like to place on record their gratitude to Indian Council of Social Science Research, New Delhi for supporting this research endeavour and to all the research subjects who contributed to the accomplishment of this study.

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