Narratives of Mothers: An Optimistic View of Raising Children with Disabilities

Priti Joshi
University of Delhi, Delhi, India

Abstract

The study explored the experiences of 49 mothers of children with disabilities through interviews at home. The children were in the age group of 5-13 years, and were studying in mainstream schools. The families resided in New Delhi, the capital of India. They were from the middle socio-economic status and followed Hinduism. The mothers described a wide range of difficulties ranging from financial, emotional to interpersonal in raising their children. However, 21 mothers among them stood out from the rest. Their narratives were optimistic and had positive perceptions. They gave positive meanings to their lives and to the child's situation despite challenges and even though the larger system viewed them negatively. The paper highlights themes that emerged as part of the journey of mothers in developing a more optimistic view of their child's situation and their own self as a person. The research has implications for family interventions.

Keywords: Optimism, families, positive coping, quality of life

1. Background

Constructions of disability vary from one culture to another, giving rise to perceptions about those with disabilities. In India, by and large, disability has been feared and regarded as a misfortune, though some impairments are less stigmatised. Children identified as disabled, although considered worthy of pity and charity, are likely to be judged as “deficient”. India has participated in almost all international conventions and conferences on special education and has been a signatory to the important declarations made by UN agencies including the recent UN Convention on the Rights of Persons with Disabilities. There are three major Acts that relate to education of disabled children, several policies, a national trust for welfare and a regulatory council to promote training of personnel (Government of India, 2010; Government of India, 2014; Government of India, 2016; Government of India, 2018). As a signatory to the Salamanca Statement, India committed itself to the development of an ‘inclusive’ system of education though very few schools are inclusive (Bhattacharya, 2010).

Although there is a stigma attached to disability in the public domain, and formal systems of support are inaccessible, inadequate or unavailable, yet individuals with a disability, like others, have the advantage of being part of a close-knit community (Joshi,
This is especially so in rural areas, where they experience some natural integration to live with dignity. Children enjoy a network of relationships generally spanning three generations, sharing special closeness with some family members. Women in the family, provide care to disabled children. But in an urban-industrialised setting, in the metros and cities, children with disability are likely to find limited acceptable social roles and fewer opportunities for interaction outside the family.

In a metropolitan city like Delhi parents, in particular mothers from the middle socio-economic status, are closely involved in children’s socialisation and education. Considering the socio-cultural-economic context in India and the limited services available for children with disabilities, it is well documented that the families experience immense stress in big city. The families raising children with disabilities are concerned about various issues that go beyond school, daily life and education. As “providers” for children, they look ahead with a deep concern for the future. A majority of families worry whether school education would be of “value in real life” and question its quality too (Singal, 2016). Parents bringing up children with moderate to severe disabilities anticipate unemployment. They worry whether life as an adult for their child would be purposeful and meaningful, and if they would find a life partner. An especially distressing question for the parents was: where would the child live and in whose care after their death? Families rely on their own resourcefulness to find answers to these questions and to rear children with disabilities for which they have received little recognition.

Earlier, families that experienced stress of any kind were viewed mainly from the deficit perspective. However, over the years there has been a shift in this perspective, towards finding out how families cope positively, what makes them feel empowered and also improves their quality of life if they are experiencing difficulties (Dunst, 2002; Dunst, Trivette, & Deal, 1994; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). The families who re-view or re-frame their challenges have more positive outcomes for their wellbeing and that of their children. This provides an entry point for professionals and educators who work with families to support their strengths rather than focus on overcoming limitations. Those families who see themselves as coping well and also effective can manage well without support of the social worker or counsellor (Hulme, 1999). Earlier these studies regarded families’ reappraisal as denial and also a distortion of reality.

With a change in emphases from a deficit perspective to a more positive view, as researchers began to enquire about family strengths as well, studies from across the world have fortunately reported optimism, and positive feelings of the parents, of children with disabilities. Several qualitative studies reported that the parents have a strong purpose in life (Stainton & Besser, 1998), and they learnt many new skills and strengths (Scorgie & Sobsey, 2000; Stainton & Besser, 1998). Some families extended their networks and made new friends (Taunt & Hastings, 2002). There are families who have reported becoming spiritual (Stainton & Besser, 1998; Taunt & Hastings, 2002)
while others became more understanding and sympathetic (Scorgie & Sobsey, 2000; Taunt & Hastings, 2002). The positive perceptions also led to viewing the future more positively (Gupta & Singal, 2016; King et al., 2009). Among families the optimism was also correlated with feeling less weighed down and stressed (Ylven, Bjorck-Akesson, & Granlund, 2006).

Focussing on positive aspects of rearing a child with disability has been generally overlooked. Attending to positive perceptions and optimistic outlook would lead to viewing the families with a different lens and build on their strengths to support adaptations and adjustments. The attention on optimism also leads to discovering what informal resources families gather to solve their difficulties and in some way challenge negative expectations and perceptions that exist in society about them.

With this in mind the present study explored positive perceptions as one of the sub-themes in the families’ experience of caring for children with disabilities. Besides listening to challenges and hardships that parents experienced, drawing out positive perceptions or coping strategies would be a resource; to build upon and apply in intervention programmes. Developing an awareness of what contributes to optimistic outlook would be important for both parents and professionals.

The purpose of the study was to explore the family experiences of rearing a child with a disability including day-to-day happenings, the meaning this experience holds for them, the family’s relationship with other people in the context of the child, child’s social network and activities, and the family’s perception of and portrayal of the child. The research also focussed drawing out adaptive and optimistic perspective and to see how families cope well with challenges in the given context.

2. Research Methodology

The participants in the study were 49 families, each with a child with special needs. Children were between 5-13 years of age, studying in mainstream schools. Eight were only children and the rest had one or two siblings. Twenty-one of them were identified as those with intellectual disability, 9 with hearing disability, 10 with physical disability and 10 with chronic illnesses. The nature of disabilities and illnesses was such that they were able to continue and cope with a school programme organised primarily for the education of “normal” children.

| Education      | No. of mothers |
|----------------|----------------|
| Secondary      | 8              |
| Graduate       | 29             |
| Postgraduate   | 12             |
| Total          | 49             |

Table 1 Education profile of mothers (N=49)
The families were from the middle socio-economic status Hindu population residing in and around Delhi, India's capital. Thirteen of the households comprised extended families, while 10 were joint and the remaining 24 were nuclear. Besides these, there was one single-parent family, comprising a mother and a daughter. Thirty-six mothers were not working outside the homes. The rest, numbering 14, were in diverse professions such as teaching, medicine, finance and law. Some were practitioners and others were dealing with administrative, clerical, research or editorial work.

Experiences of bringing up a child with special needs were elicited through an interview guide with a set of open-ended questions. All interviews with the mothers were focused on the issue of caring for a child considered “not-normal” with a view to understanding their belief systems and perceptions about the child. The interview explored the family’s total experience of rearing a child with a disability including day-to-day happenings. Interviews were conducted at home. Seven fathers were also present during the visit to the families. Only two fathers contributed to the discussion which took place.

A qualitative methodology with an inductive approach was adopted to analyse and describe the interview responses. A content analyses was carried out (Berg, 1995; Weber, 1985) was put to use, where emerging themes and categories were coded through reading the transcripts repeatedly.

These interviews were analysed to ascertain the meaning of disability for parents and issues important to them in the given socio-cultural context. Thematic analysis was used to analyse the data and themes that emerged were grouped together. The comments and narratives of the participants are retained so that their voices could be heard.

3. Results

The mothers recounted a wide range of experiences about bringing up their children. In the day-to-day rearing of children fathers were less involved. Several commonalties were present in their accounts related to the unique challenges and worries of rearing children with disabilities. Many experiences were common to the families which was clear from the frequency of their mention, the intensity with which these experiences were recounted and by the reported impact on their lives. However, subtle differences between families’ perspectives towards the children were observed as a result of variation in families’ circumstances and their belief systems. Mothers recalled crises they had faced or were facing at each point of transition, from discovery of the impairment, to starting school, helping the child to cope with school and as the child got older, to anxiety about future with limited alternatives. The second theme was about the family's difficult personal and social experience. They also reported being subject to hardships in obtaining services and derived support from her own or at times husband’s parents (Alur, 2001). Another parental concern was their apprehensions about their child’s image and identity.
3.1 The optimism of the mothers

The narratives of 21 mothers about children’s life situation were inclusive of many positive elements. The perceptions of these families about children’s disability were positive even though the larger system generally viewed their situation in negative terms (Gupta & Singal, 2004). The families perceived their situations in ways different from the rest of the families in the study even though they were in similar circumstances as the rest and under considerable stress for various reasons.

It was noted that if children did not have many medical problems, mothers reported more positive feelings, further if the nature of disability was less severe, narratives were more optimistic. Another factor which led to more positive perceptions was strong family support in joint or extended families. In referring to the child, the conversations were permeated with phrases such as “in our family”, “we have decided”, “our child” etc. In 10 families 3-4 members were present during the interview, talking jointly about the child and their experiences. Parents who were considered high ranking professionals received a positive response at school, and this too shaped their positive perceptions. Though mothers’ education alone nor her education was related to optimism.

Three themes could be identified which emerged as part of the re-appraisal. These were, the nature of families’ involvement with the children, the ability to reframe perspective about the children as well as their own selves over time. From the total of 49, 21 families (43%) mentioned ideas related to at least one theme, while 15 (30%) among them mentioned elements integral to two themes while all the three themes recurred in the accounts of 8 (16%) among them. An explanation for these positive perceptions lay in the meaning families gave to their lives and the manner in which they conceptualised and regarded their child. As a result of this many were involved in “finding solution, doing things to bring a change in the child’s life”. These three themes have been elucidated in the following sections: 3.1 A sense of control and competence, 3.2 Redefinition of the child, and 3.3 Redefinition of the meaning of life and self

3.2 A Sense of Control and Competence

Chapter For the parents, sources of information, support systems for children’s development and their education were limited, except for one of the schools where ten children were studying. Parents were advised on various issues if they approached the school staff. But to search and enrol the child in another programme to suit the child’s changing needs was left to the parents, a tough agenda in a large city because neither adequate information was available nor were enough services. Thus, at each stage in the child’s life parents needed to explore what was available for education or treatment and select an alternative to suit the child’s needs and family’s expectations. What they managed to achieve depended on personal resourcefulness. Additionally, parents were challenged by unexpected situations and had to take decisions without consultation with professionals.
In this context, 14 (29%) mothers talked about their involvement in seeking new information about the child’s impairment, getting in touch with parents of disabled children, figuring out what the child could be taught considering potential for development, searching for a possible cure, identifying vocational alternatives or trying out new ways of teaching; doing their best in the given situation. This was an ongoing process. The mothers reported to be involved in one thing after another. While doing so they felt a sense of control over demanding situations and felt competent in making a difference to their children’s lives. Tina’s mother reported that she maintained a scrap-book in which she ‘pasted’ and filed any clipping or material related to epilepsy including relevant addresses. This is what she said: “My scrap-book has grown this fat (she gestured with her hands) - many times I have found useful information in it. In fact, I have shared material from this with other parents. I feel that I am doing as much as I can to be an aware mother who is always ready to face new and challenging situations”.

It did not matter so much whether the outcome was ‘successful’, but the sense of purpose led the families forward. The families did believe in the principle of karma, the belief in one’s past actions, as an explanation for suffering in one’s life. The subjective meaning of belief in karma may range from a fatalistic attitude to hope and expectations; from a sense of helplessness to faith in action. In the case of mothers who believed so, it signified a faith in action. This belief keeps the faith in just world alive even under very adverse conditions and sustains the hope that good deeds will ultimately result in good outcomes (Gokhale, 1961). In the case of Dhwani’s mother, giving up her job as an engineer did not cause conflict. She was extremely satisfied with her daily schedule which involved taking her son to school, waiting there till the school got over and taking Dhwani back home. Their home was over 30 kilometres away from the school and it was not possible for her to go back home and return to pick up her son. In the evening she was occupied with a visit to the physiotherapist. She was convinced that her decision to leave a well-paid job was a correct one although her friends and family had suggested other alternatives. The belief that she had done her best for the child and the input given by her would work in the long run, kept her going.

In contrast to these belief systems, an equal number of mothers lived with the perceptions that they had not done enough for their children or it was too late to put things on the right track, thereby experiencing guilt and lacking a sense of purpose. The mother of a child with hearing impairment said: “The time to work hard for my child is gone. It is too late to do anything. I don’t think much is in my hands. I don’t even know what is possible. Not tried enough. Cheema’s mother puts in a lot of time. Anyway, I can’t manage much”.

3.3 Redefinition of the Child

A change that had taken place over the past couple of years in the manner in which mothers regarded their children and expectations held from them was another theme that emerged from the interviews. The mothers recalled that as they began to view
children with a focus on abilities, interests and unique characteristics, it led to a change in their definitions. As a consequence, they began to view and value their children as persons and not just as disabled children who required to be transformed and trained.

This took place in a number of ways as reported by 11(22%) mothers. One mother said she stopped teaching her daughter, Neha, something she used to be occupied with almost all the time, never recognising what Neha herself wanted. The mother became aware of her interactive style with Neha, that was mainly instruction based where the effort was to shape the child’s behaviour. Redirecting her attention to Neha’s wishes became a fulfilling experience for the mother. So she took cue from what Neha wanted and began to view the child as the one who could guide her. Similarly, Neelesh’s mother realised that it would be more meaningful for her son to be engaged in activities that he found worthwhile rather than training him for reading or writing. So, she began to focus on his interests. Another mother mentioned that she had become more patient and tolerant towards her son’s actions such as flapping of hands or drooling. She did not see these behaviours as bothersome or repulsive. Iksha’s mother emphasised that while evaluating her daughter’s actions or taking decisions for her, she did so with affection. Comparison with others did not figure in her thoughts any more. In this way the mother had been able to stop herself from forcing the daughter to study and live up to social expectations. Some families derived strength form other parents who were coping with many more difficulties and were able to see positive aspects in their child’s condition. One mother said “My child is better off than many others. I always wished for things to be better. But then I realised that things could have been worse. I notice children who can’t talk, or walk, some are completely bedridden and yet their parents have a smile for everyone around…”

Rupesh’s mother reported that a change had come about in the definition of her son’s condition as a result of a meeting with a relative. In a long discussion, this aunt of the mother emphasised that mental retardation was not a disability as the child could do physical work which was as important. This helped the mother to focus attention on the child’s abilities, leading to a positive relationship between them. She said, “I began to see other aspects of him. My aunt guided me to do so. I began to realise that if he is not so bright it is only one side of him. Having a disability is one aspect of life and it is not such an important aspect”.

Another mother reflected on her changed perceptions regarding her son “Mohsin seemed like a problem. You know what I mean. That this child won’t have a job, not get married, what will happen to him… but now I feel very differently. He is very loving and affectionate. And I feel very close to him. Also he will always be with me. in my old age he will also be a companion. Other children go away or get too involved with their families. He will be there for me. I feel very relaxed”.

A school that pressured the child to do well and attended to only those students who were high achievers presented their children in a poor light was noted by three
mothers. In the private schools where their children were presently studying, there was an undue emphasis on academic performance and upon demonstration of success. The setting highlighted the children’s “incompetence”. The families contemplated shifting children to state run schools with a more “relaxed” atmosphere where children were left on their own. The mothers were aware that the schools were infamous for poor teaching and hence used the word “relaxed”. However, they realised what they wanted for their sons or daughters. A setting where they could meet and be with other children and formal learning was no more an agenda. The mothers’ accounts brought out a realisation that at times a particular context defined the child disadvantageously. It was in their hand to make a change in the setting rather than the child. One of the mothers said, “I want my child to have good time at school. Why should she be made to feel that she is no-good. I will put her in a government school. The child would be less tense. And also, in a place (referring to the government school) where everyone speaks Hindi (the child’s first language and one that was spoken at home) she is more comfortable. I understand what would make her happy, no point in having goals which will make her life tough”.

3.4 Redefinition of the Meaning of Life and Self

Elements in mothers’ accounts indicated that they were active in evaluating and examining the meaning of life in the context of goals for their children and the experience of suffering and happiness. Reflections on these issues had led 7 (14%) mothers to redefine their expectations, themselves and the outlook towards their situation. One of them reflected on her life, “If you see your child suffer and lead a life where ordinary things also become tough, it makes you think…. this situation gives you an ability to stand back and reflect. So, what are we running after is a question I often ask myself? Can I be happy only if my daughter is perfect? There are other important things such as becoming a good human being. I mean for myself also for my child”.

The mothers viewed positive aspect of suffering. Their philosophy of living reflected the Eastern perspective that considers suffering as a life process, as a way to salvation and liberation and necessary for purifying the soul (Palsane & Lam, 1996). The consequences of suffering are seen to be mental pain, despair and exhaustion. The mediators are dharma (right conduct) and detachment. The latter enables the individual to view pleasure and pain with equanimity, not being too involved in the objects of pleasure and not too concerned with the avoidance of suffering. Thus the means of remedy particularly when suffering arises from mental pain lies in the reconstruction of images of what the world is and what we ourselves are in relation to the world as perceived by us (Paranjpe, 1996). In the case of these seven families, this philosophical viewpoint was reflected in the re-framing perspective and the serenity with which they were dealing with suffering and pain (Poston & Turnbull, 2004). Thus, the perceptions of these families about children’s disability were inclusive of many positive elements and they stood out as different families in comparison to the rest of the 42 families.
The development of personal qualities which would give them the strength to deal with challenging circumstances was emphasised rather than pressuring the child to improve. With faith in God, the child’s condition generally regarded as a misfortune, was being faced with equanimity, was conveyed by the mothers. Building on her own strengths and identifying the child’s abilities were important in reconstructing these images believed to be true about disability.

Table 2 Mothers’ Redefinition of the Meaning of Life and Self, n= 7

| Key Themes                  | Illustrative Quotes                                                                                                                                                                                                 |
|-----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Meaning of life and         | Looking at the positive aspects of our life, we derive happiness from other things in life and try to downplay Meenu’s illness. We focus attention on manageable tasks, rather than worry about the future. Let Namish be a sanyasi (the one who renounces the world), it will free him from the rat-race of this life. Suffering has taught me a lot and it has its own rewards. It makes me a better human being. Suffering brings me closer to God. |
| expectations                |                                                                                                                                                                                                                       |
| **Self**                    |                                                                                                                                                                                                                       |
| I am becoming indifferent to | those who dismiss my child, thus many things have stopped bothering me.                                                                                                                                              |
| those who dismiss my child,  | I am a different person, become tolerant and less selfish. To have these qualities is more important than achieving other goals.                                                                                             |
| thus many things have        | To get things done for her, I fight and present my views more forcefully.                                                                                                                                              |
| stopped bothering me.       | I look after my child as best as I can, and the rest is left to God. I spend free time in *satsang* (singing hymns as part of a group), go to the temple or say prayers at home. This fixed routine has made me free of depressing thoughts. |

4. Conclusions

The mothers’ accounts highlighted their major concerns regarding children. In talking about their sons and daughters, the mothers spoke of their own selves and their lives with a positive orientation. The families displayed unusual strength in coping with everyday challenges as well as dealing with long-term goals. The issues that caused worry and required the families’ attention, points to nature of support they required.

A majority had become indifferent to the views held by others and focused on positive aspects of rearing a child with disability. Over a period of time, they had begun to regard the children, their own selves and life situation in ways different from the larger society that upholds a negative view of disability. These views have many implications for any programme that supports children’s education particularly professionals who do not acknowledge families’ strengths and the ability to adapt to difficult circumstances. Focussing on the positive picture can redress the balance and provide another framework to understand families bringing-up children with disabilities.
The only setting which was a point of contact with professionals was the child’s school. In the given context, schools have the potential to support children and families. For schools and teachers to be responsive to parents, it is important that the beliefs and skills parents draw on to rear their child within challenging personal-social circumstances be understood and shared with other parents in similar situations.

The present study has several implications for emerging from positive perceptions of the mothers about their children with disabilities. It would be important to know what kind of perceptions as well as coping actions benefit families. This information would be meaningful for practitioners to plan interventions. It would also be important to find out if fathers too have optimistic views and whether these are similar to the mothers. If families could be empowered to find more positive outlook and feelings, it would lead to reducing their stress and hardship.

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