

Parenting a Child With Down Syndrome: A Phenomenographic Study

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Abstract

In this study, mothers' experiences of parenting a child with Down syndrome are explored. The research employed a phenomenographic methodology. Interviews were conducted with five mothers who had a child with Down syndrome between the ages of three to eight years. The study was conducted in Singapore. Six qualitatively different aspects of the parenting experience are identified. The findings show, despite an immense impact on family life, the mothers did not view their situation in a negative way. Their resilience was evident, although they reported that significant adjustments were made. While the sample size in this exploratory study is small, the findings provide a new understanding about parenting a child with Down syndrome within a particular cultural context.

While many quantitative studies have examined the experience of families who have a child with disability (e.g., Ainge, Covin, & Baker, 1998; Benett, DeLuca, & Allen, 1996; Bower, Chant, & Chatwin, 1998; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001), only a few have employed a qualitative research approach. In this qualitative study, commonalities and the variations of family experiences in parenting a young child with Down syndrome in Singapore are explored. The research extends understanding about the experiences of families who have a child with intellectual disability, within an Asian family context. However, the participation of Asian families does not limit the relevance of the findings to other cultural contexts. The findings provide opportunities to consider personal and professional assumptions made about families and disability across cultural contexts. Within any culture, beliefs and practices are often "unrecognized" because of their "everyday" familiarity. It is only when the beliefs and practices from other cultural groups are considered, that one's personal assumptions about families become more apparent. Research about how ethnicity and culture shape family experiences, provides an opportunity to evaluate assumptions that families also hold on children's development (Parke, 2004; Pumariega, Rogers, & Rothe, 2005).

Most of the research on the experiences of families who have a child with a disability indicates that, although there may be commonalities in the parenting experiences, the impact differs considerably among families (Bower et al., 1998; Hanson, 2003; Muscott, 2001). In a meta-analysis of studies since 1975, that examined marital strain in families who had a child with a disability, Risdal and Singer (2004) reported that although there was a negative impact, the effect was much smaller than expected. 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. Cunningham (1996) noted that the overriding impression of families with a child with Down syndrome is one of normality. The factors influencing the well-being of the family are largely the same as those influencing any family. He cited evidence that pointed to positive effects on the family and their attitudes towards life because the families have strengths and resources to manage the challenges. 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.

Hanson (2003) conducted a long-term follow-up, after 25 years, with families who had a child with Down syndrome and who had participated in an early intervention program. The research explored the parents' parenting experiences across that time span. Significant challenges that were recalled by the families included coping with health and medical problems and events that related to teasing and ostracism of their child by others. Parents also expressed disappointment with the overall lack of support that was available to them through formal services and the poor quality of these services. However, the study also revealed positive outcomes including the joy that the child had brought to the family and the personal growth of family members as a consequence of being a parent or sibling to a child with Down syndrome.

In this study, the parenting and family experiences of mothers of young children with Down syndrome, aged three to eight years, are explored. The research sought to identify the commonalities and variations in families' experiences. Key questions for the research were: What is the impact of the birth of a Down syndrome child on family life? What is the experience of parenting a child with Down syndrome in Singapore?

Method

This research employed a phenomenographic approach (Marton, 1981; Marton, 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 characterize 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, conceptualize and understand a particular experience (Marton, 1986). The findings from this phenomenographic analysis represent the collective experience of parenting a child with Down syndrome while acknowledging that there are individual variations in this experience. While this 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.

Participants

With the assistance of the Down Syndrome Association in Singapore, five mothers were contacted and invited to participate in the study. The criteria for participation included having a child with Down syndrome between the ages of three and eight years old, and being able to communicate fluently in English. The participants were all of Chinese background and held postsecondary education qualifications. All the participants were in their thirties when their child was born, and all participants were married. In each family, the child with Down syndrome had older siblings; thus, the participants had previous experience in parenting. Pseudonyms are used in the report of the findings. The participants are called Jill, Mandy, Joanne, Liz and Eve. These names were selected because each participant, despite being Chinese and possessing a given Chinese name, also carried a Western name.

Interviews

The data collection process in phenomenography is usually through interviews which allow maximum freedom for participants to describe their experiences (Ashworth & Lucas, 2000). Each interview began with the following questions. "How would you describe you, your family, and your family life?" "In what ways do you believe your family is the same or different to other families?" Other guiding questions tapped the nature and level of support that the mothers received

from others, including the immediate and extended family, and the community. Prompts such as, "Can you give an example of that?" and "Can you tell me more about that?" were used in order to elicit rich descriptions of experiences. The mothers' own interpretation of any questions dictated the shape, course, and content of the interviews. The five mothers were open and willing to share their experiences.

Analysis

Phenomenographic analysis is a holistic process. The critical features of the phenomenon (or phenomena) under investigation are represented as categories of description (Åkerlind, 2002; Ryan, 2000). 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. The collective structure of these categories is represented by the outcome space which diagrammatically illustrates the relationships between the categories of description. The validity of phenomenographic studies is based on the researchers' justification for the representation of the categories of description and structure of the outcome space that can be judged by the reader as credible and trustworthy (Cope, 2002).

The analysis for this study involved the two authors who independently at first and then collectively arrived at the final set of categories that describe the variations evident in how mothers described the phenomenon being investigated. The process for review of the interview transcripts was similar to that employed by Dean (1994). The process involved familiarization with each transcript and its content, then stages of reflection, comparison of ideas, condensation, explication, and categorization and articulation of the categories of description. Numerous reviews of the transcriptions provided a depth of understanding of each mother's account of her experience. As key meanings were constituted, the dimensions of variation within categories and the structural relationships between the categories were identified. When a consistent set of categories was decided, illustrative statements of the categories were selected from the interviews transcripts.

Results

The findings are reported in two sections. The first section explains the categories of description and the commonalities and variations within those categories as experienced by the participants. Each category of description includes a label and a description of the meaning of the conception associated with that category (Åkerlind, 2002). Second, the structural component outlines how a particular category is related to the overall experience. The second section describes the outcome space in which the relationships between the categories of description are elaborated.

Categories of Description

Six categories of description reflecting key variations of meaning emerged from the analysis. The commonalities and variations in mothers' descriptions are illustrated with excerpts from the transcripts. The quotes provide illustrative examples of the category that supplement the abstract description.

The categories are:

- Category 1: A child with Down syndrome – the impact
- Category 2: Family relationships
- Category 3: Parenting expectations and practices
- Category 4: Social support
- Category 5: Formal services
- Category 6: Societal and community acceptance

Category 1: A child with Down syndrome – the impact

This core category describes the initial impact on the mother of the birth of a child with Down syndrome. The circumstances under which this knowledge is received are clearly recalled by the mothers because this is a significant event that is maintained as a part of the ongoing family narrative. The impact of this experience is evaluated and reevaluated over time as the mothers consider the changes in their lives that the event has brought. The timing of the event provides variation within this category, similar to the time when the knowledge is shared with others.

For Eve, Joanne, Liz and Mandy, the knowledge that their child had Down syndrome came when the child was born. For Jill, the knowledge was acquired prior to the birth because of a prenatal diagnosis. For all the mothers, except Eve, this knowledge brought trepidation and apprehension

because they possessed little knowledge about Down syndrome. As a nurse, Eve was more informed about the implications, but was still overwhelmed by the news.

Mandy said:

It was like a shattered dream for me ... I had no idea what Down syndrome was but I knew that it's something that is not normal. Something that is totally different from what I expected and it was like a blank. My mind went totally blank with a lot of question marks.

For Eve, the impact was significant but different because she was more aware of the condition:

Yes I am a nurse ... the moment she was born the staff were quieter than normal. So I knew something was not right. When I first looked at her I told them she was Downs.... They held back a little bit, because they were not sure how I would react to having a Down syndrome [child].... I would say I did accept her but then I still asked myself the question, "Why me, as well?" ... That is the normal question to ask, "Why me?"

For all participants, an additional concern was how and when to share this knowledge with others. Joanne said:

I was in shock. I did not know how to react because I never expected him to have this condition; even my husband as well, when hearing the news, he actually broke down. For months, I really did not take it so well.... I was in denial, I was like in total pain and my family as well.

All participants commented on the personal change over time that had resulted as a consequence of the birth of their child. Mandy indicated:

We have learnt a lot of things through him; we learnt unconditional love and we learnt a lot, such as, not taking things for granted. When I look at things now, I say I look at the positive way first because previously when negative things happen usually, I will feel sad but now I look at it from a different angle.... I know how to handle things more positively. I am not so concerned about how others

look at me because of him any more.... I should say it has helped me to become a better person to understand life; looking at life with different values.

The category illustrates the initial and ongoing effect that the birth of the child with Down syndrome had on the mother, as well as the significance impact of the event on other family members.

Category 2: Family relationships

This category is complex with sub-categories related to the subsystems in family relationships: the marital relationship, sibling relationships and relationships with the extended family. It identifies how the child's condition has affected the closeness and cohesion of the immediate and extended family. It includes individuals' relationships with the Down syndrome child, but also the nature of the relationships between family members that do not include the child but which are affected by the presence of the child. It also reflects the level of acceptance of the child by family members.

All participants described their family relationships as similar to all families, as Joanne noted:

I think we are the same as other families. My husband works and my husband takes care of the family. In between, we try to do things together. Basically I think this is what most families are doing.

Marital relationship. All participants highlighted the importance of support from their partners. Liz noted how she became less self-centred and focused on her career and how the child had strengthened the relationship with her husband:

If I look at it, the positive side, I think it is more positive than negative really ... maybe we would have been divorced, maybe because of my career-minded thinking before.

Sibling relationships. Siblings accepted their brother or sister with Down syndrome. Age of the sibling was an influence but also parents needed to make their other children aware of the condition. Joanne mentions the initial feelings of her other son that indicated recognition of difference:

Yes he understands but initially he kept asking, "Mummy why, why is brother like...?" He says, "I don't want my brother to look like this," and he questions every time. But now he is accepting him and now he is saying my brother is fine; he's the same as any other normal kid.

Extended family relationships. Liz relates that, although her in-laws are now very supportive, cultural values played a role in their initial reaction to their son:

At first they really didn't even want to look at him, but slowly they now start to accept him... Being Chinese, very typical Chinese and my husband is the only son, they want somebody to take the name, of the family I mean. So, fortunately I have another son.

Category 3: Parenting expectations and practices

This category represents how mothers perceived their parenting role in relation to their child and the practices in which they engaged to support their child's learning and development. There was awareness by all the mothers of the importance of optimal learning experiences for their child to achieve his or her potential. There was recognition that a major goal in parenting is to ensure the child can become independent irrespective of any intellectual disability. Eve's comments highlighted the importance of this goal:

And self-help, we try to get her to do [things for] herself. Although we still have to help her a lot though. I prefer her to do things for herself rather than depending on us to help her along the way.

Joanne highlighted her concern to balance the needs of both her children but also to extend opportunities for her son with Down syndrome:

I am spending a lot of time trying to give him as much as possible and I hope that I have not neglected my elder boy, because he needs also attention, so I am trying to balance up actually... I wish [any] one day can have longer hours, because I don't have enough time really for the two of them. And not only his special school, I am also putting him in a child care to mingle or to interact with regular kids – to have him improve in every area.

Category 4: Social support

All mothers placed an emphasis on the importance of social support from outside the family. Old friends who were understanding and empathic were important but extensions to existing social networks had also occurred through contact with other parents who had a child with Down syndrome. Jill's comments illustrate this category:

I think for us family and friends have always been important.... When we first found that she could possibly have Down syndrome, and then we found out that she had a defective heart, we knew that our friends grieved for us. For my husband and I, I think the greatest privilege now is that because of her we now have made friends and gained entry into a world that we never would ever have known.

Mandy described how she developed her own support group with other parents who had a child with Down syndrome of about the same age:

I have got to know a group of friends and all the mothers that joined; all have children with Down syndrome. So we actually share the same concerns and we have the same things to talk about every time, so we always share and exchange views.

Category 5: Formal services

Families deal with formal services. This category represents the mothers' experiences with health care services primarily. It focused on mothers' experiences with professionals. They had mixed responses about the quality of the information and support received. Mandy reported:

The health care workers in the hospital where I had my delivery did not handle the situation sensitively enough. If they had, probably at that very moment, my feelings, my emotions could have been less affected. Because I feel that when they tried not to talk about it, it's like everybody is like trying to shun away from it and that made me worse. ... Like it made you feel so ashamed to even mention it. So I think because of that it totally gave us a very wrong impression of what actually this is all about. I find that the more you want to avoid talking the worse we will feel.

Mandy also had found a lack of support within the child care and early education system.

Not every school accepts children with Down syndrome. I went with him to a few child care [centres] and two of them turned him down. I said, "Okay, if you don't welcome me, I will go somewhere else." You are knocking at all the doors.... But now, that they open it I can choose which school I want to go.... I choose which class I want him to be placed and I will talk to the teacher first. I make sure that this teacher is very receptive and [does] not have negative thinking about children with Down syndrome.

Category 6: Societal and community acceptance

Throughout the interviews, mothers referred often to the broader societal context in which they lived and their awareness of the possibilities of social exclusion for them and their child.

Much depends on the mothers' attitude as reflected in Mandy's comments:

I bring him out very freely. I do not bring him out only to selective places. Wherever we go we bring him along. Society now accepts this disability. Of course, we still do get people staring, because of their classical look but this has never affected how I feel.... In fact sometimes I have this urge to go that person that is staring, to ask them if they want to find out more about anything that they are not sure [about].

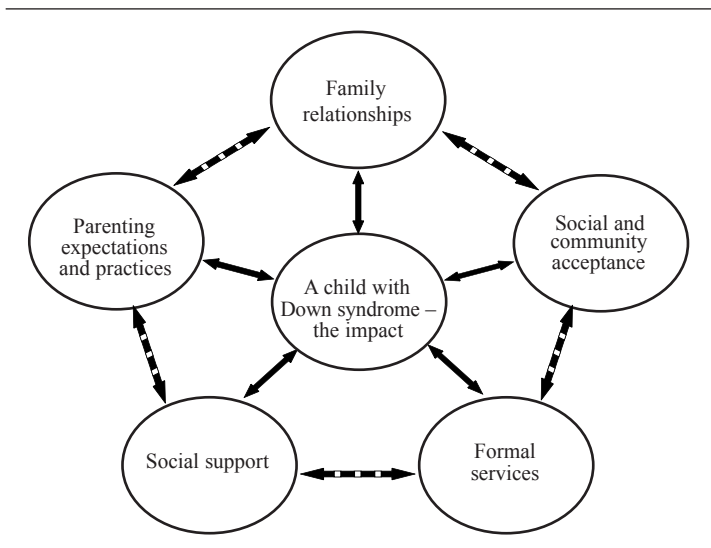
Jill highlighted the need to advocate for the rights of all children:

I think every child has the right to be educated whether or not they are a Down syndrome child, or an autistic child, or a dyslexic child, or a normal child but I think Singapore has really spent too much of time and focus on the excellent normal child.

Structure Of The Variation Of Family Experiences

The outcome space which emerged from mothers' conceptions is represented in Figure 1. The birth of a child with Down syndrome is a pivotal change experience which affects all subsequent experiences. The outcome space emphasizes the strong bidirectional relationship between the core category and other categories. Each category influences another. Family relationships represent a category that has perhaps the strongest bidirectional relations with the core category. This overall conceptualization draws attention to the importance of the individual experience and the adjustments needed to be made. Accommodations are made as mothers move on in their lives to focus on their child's learning and development. They are supported in this process by a range of informal and formal supports, including the extended family. The everyday life of each family is also embedded within the broader social context and the values, beliefs and practices within that context which have an impact on the acceptance towards individuals with disabilities and their families.

Figure 1. Mothers' conceptions of experience in parenting a child with Down syndrome



Discussion

Strong advocacy for the rights of individuals with disabilities over the last 30 years has resulted in increased societal understanding and acceptance of intellectual disability. Parents have played a significant advocacy role in this shift in attitudes as they sought to increase the social and educational opportunities available to their children. Research exploring parental experiences provides knowledge about family strengths and resources, as well as the needs of families that could enhance their quality of life (Turnbull & Turnbull, 2002). Higher expectations of the capabilities of children with intellectual disabilities have led to significant gains in their demonstrated educational achievements and have provided them with more opportunities to participate in society. While many barriers to increased social and education participation still exist, there is optimism that progress continues to be made and that benefits accrue to families when the societal context is supportive of their children with intellectual handicaps.

The study adds to the limited literature on the influence of ethnicity and culture on parenting a child with a disability. Much of research on families' experiences has been conducted in western cultures, especially in the United States, with primary representation of Caucasian and Afro-American ethnic groups (Parke, 2004). With increased awareness of the nature and the diversity of Asian cultural values with respect to disability, this research contributes understanding of families' experiences within a specific culture. Cultural differences in how Asian mothers of children with intellectual disability in the Singapore context perceived available support were investigated by Ow, Ngoh, and Goh (2004). They reported differences between Chinese and Muslim cultures and indicated the need for professionals to become more familiar with different cultural values in their work with families.

Phenomenographic research highlights that the same event has a number of different facets. Phenomenography respects the uniqueness of individual experiences and subjectivities as well as the diversity of influences that shape those experiences. At the same time, it can provide a sensitive way of comparing and categorizing across individual experiences. In this study, phenomenography elicited mothers' perceptions of parenting a child with Down syndrome that can inform professional knowledge. In other studies, such an outcome has been termed developmental phenomenography, since the knowledge gained can lead to applications in communities of practice (Bowden, 2000).

Family-centred practice requires sensitivity and understanding of family needs by social workers, health care workers and teachers. With sensitivity

and understanding, parents can then make effective decisions in the interests of their child and in the context of the family. In the early childhood years, a foundation can be built that can develop the capacities of families to deal with future transitions for the child. The research findings provide understanding that having a child with Down syndrome or, for that matter any disability, does not involve a single perspective and needs to encompass different family viewpoints, and knowledge of their resources to cope with any increased demands that may arise from their child's disability.

While this research focused on maternal perspectives, it does not seek to exclude the important role that fathers have in relation to their children. This research points to a need for other research in this area which seeks the views of other family members, including fathers and siblings. This will enable the development of a more comprehensive model for understanding the commonalities and the variations in family experiences in their parenting of a young child with a disability.

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