Abstract

The aim of this research was to explore the experience of parenting a child who has been diagnosed with a developmental disability. The in-depth interviews were semi-structured and open-ended, covering topics such as the positive and negative experiences, and time demand in raising a child who has a developmental disability, their effects on family relationship and on physical and mental health of the parents, and the strategies for managing the negative experiences. Overall, the participants indicated that parenting a child with a developmental disability is both challenging and rewarding, depending on the circumstances facing parents in a particular day. The findings are interpreted in five thematic structures: (1) negotiating joys and sorrows, (2) physical and mental exhaustion, (3) negotiating with family matters, (4) social stigma, and (5) hope in the midst of despair; each of which comprised several sub-themes/categories. The discussion includes implications of the findings.

Keywords: developmental disability; parents; child; challenges; rewards; stigma
Introduction

The experience of parenting children with developmental disabilities can be positive (e.g., joyful and happy feelings) or negative (e.g., stress, burden, sorrow, physical exhaustion etc.) or a combination of both, depending on the severity of cases. Parenting children who are diagnosed with having autism, cerebral palsy, Down syndrome, Fetal Alcohol Spectrum Disorders (FASD), and other types of disabilities pose different and increased challenges compared to raising children who do not have a disability. Reichman, Corman, and Noonan (2008) suggested several ways in which parenting a child with a disability is different from parenting a child without a disability. Children with autism and attention deficit disorders often require additional primary care as well as more specialized and long-term medical care. Functional limitations may necessitate structural or technical modifications in the physical home environment. A child’s disability may require parents to seek educational and recreational accommodations to ensure that the child has opportunities that are equal to those of a child without a disability. Finally, as the child ages, specialized rehabilitation programs may be necessary to ensure a positive transition to adulthood. While there are numerous programs and organizations to provide parents of children with disabilities with social and financial support, navigating and coordinating these benefit programs can be a challenge. Overall, parents of a child with a disability may encounter a unique set of challenges that are not faced by parents of a child without a disability (Reichman et al., 2008).

In general, research focusing on the experiences of parents of children with intellectual and developmental disabilities has been dominated by a medical model of disability (Gray, 1994). As such, a body of research focuses upon the burden and stress (defined here as a negative condition affecting one’s well-being) of having a child with a disability (e.g., Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Gray, 1994; Weiss, 2002). In addition, a number of quantitative studies focus upon the correlation between parenting a child with intellectual and developmental disabilities and parents’ stress, sense of coherence, self-esteem and other psychosocial aspects affecting their health and well-being. There is relatively little research on parental qualitative experiences of raising a child with a developmental disability, experiences of negotiating with burden and joys of parenting, and experiences of their own processes of adjustment and coping, and its effect on themselves and the family (Goddard, Lehr, & Lapadat, 2000).

This research project moderately draws upon an eco-cultural theory to explore parental experience of raising their child who has been diagnosed with a developmental disability. This eco-cultural perspective takes into account the physical and social context of the child and family (Weisner, 2002). Studies from eco-cultural perspective examine disability and adaptation to it from the point of view of family members (Weisner, 2002). In this study, I explore the challenges and enjoyments that parents experience in raising a child with a developmental disability, and its effect on them and other family members. In addition, I examine the strategies adopted by parents to manage their negative experiences. In this way, parents’ own experiences
with the situation are reflected through their stories of hope and distress. As such, I am interested in exploring the ‘how question’ of the process of negotiating both personal stress and social stigma when raising children with developmental disabilities, rather than ‘what kind of stress’ the parents encounter. From this research, I aim to answer the following questions:

1. What are the experiences of a parent whose child has been diagnosed with a developmental disability?
2. What effects do these experiences have on those parents and their family members?
3. What are the mechanisms adopted by parents in managing their negative experiences?

Review of Literature

Research on intellectual and developmental disabilities focuses on the psycho-social and economic consequences of parenting and care-giving. Many of the studies in this area deal with the issue of stress, coping, and psychological health outcomes in relation to managing and caring for those diagnosed with autism, attention deficit hyperactivity disorder (ADHD), cerebral palsy, Down syndrome etc. Both quantitative and qualitative studies have addressed the issue. In a qualitative study conducted in British Columbia, Goddard et al. (2000) found that in telling their stories, parents of children with disabilities made stimulating and positive statements about dealing with the issue in their lives, and shared their dissatisfactions, sorrows, and joys poignantly, sincerely, and often humorously. Goddard et al. (2000) discovered four pattern categories in their stories: (a) stories about assumptions (e.g., negative views and stereotypes); (b) stories about dealing with difference (e.g., affective/ emotional issues, assessments of ‘normal’ parenting, and making comparisons); (c) stories about professionals (e.g., early intervention, rehabilitation, schools, behavior management specialists, medical professionals, and social services); and (d) stories about disability (e.g., discourses, diagnosis and labeling, and non-pathological views in existing social structures, etc.). They also found that parents talked not only about their grief and remorse, but also how these issues around parenting children with disabilities could be situated in prevailing social discourse, deconstructed, and eventually reconstructed through emphasizing on acceptance, optimism, humor, rewards, and empowerment.

By adopting the process model of stress and coping, a recent quantitative study conducted in Alberta reported that family adjustment to childhood disability was associated with facets of strength in mothers’ psychological coping; specifically, their ability to perceive positive family consequences of childhood disability and to maintain higher percentages of positive emotion in their daily activities (Trute, Benzies, Worthington, Reddon, & Moore, 2010). Trute et al. (2010) showed that family stress associated with caring for a child with serious intellectual or developmental disability might be perceived as high, but this did not result in family pathology or family maladjustment; rather, higher level of positive appraisals that mothers identified (e.g., improved family values, sensitivity to others in the community, heightened spirituality, etc.)
were associated with overall higher adjustment of the family to child’s disability. Contrarily, a study of families with young adults with intellectual disabilities found that behavior and mental health problems at young adulthood were associated with negative impacts on the family (McIntyre, Blacher, & Baker, 2002).

A number of studies have focused on coping strategies used by parents of children with disabilities (Grant & Whittell, 2000; Heiman, 2002; Holmbeck et al., 1997; Judge, 1998; Li-Tsang, Yau, & Yuen, 2001; Wilgosh, Scorgie, & Fleming, 2000). Many researchers have adopted the view that families of children with an intellectual or developmental disability are not generally characterized by high levels of pathology, but recognize the positive effects that a child with a disability can have on the family (Green, 2007; Hastings, Allen, McDermott, & Still, 2002; Hastings, Beck, & Hill, 2005; Hastings & Taunt, 2002). Research also found that problem-focused coping strategies were positively associated with family strengths, less parenting stress, less psychological distress, and greater emotional well-being, including family confidence and acceptance of challenges in families of young children with disabilities (Judge, 1998). Moreover, Ferguson (2002: 129) asserted that research increasingly shows “a significant number of parents actually report numerous benefits and positive outcomes for their families associated with raising a child with disabilities” (e.g., coping skills, family harmony, spiritual growth, communication, and parental roles sharing).

Prior research also suggested some challenges that might place additional pressure on family relationships. Dyson (1997) indicated that parents of school-aged children with developmental disabilities experienced greater and more frequent stress because of their parenting demands compared to parents of children without disabilities. Seltzer et al. (2001) found that parents of children with intellectual and developmental disabilities reported lower rates of social participation than parents of children without disabilities, perhaps due to increased financial strain and more time-consuming childcare demands. Studies have shown that children with disabilities more often grow up in family environments that are in poverty and lower in socio-economic status (Rogers & Hogan, 2003; Wells, Sandefur, & Hogan, 2003), further increasing their developmental risks.

Numerous studies have pointed to the importance of the parent-child relationship. The importance of this parent-child relationship may be even more vital for children with intellectual and developmental disabilities. For instance, children with disabilities often require more extensive caregiving, parental monitoring, and financial support compared to children without disabilities (Newacheck, Inkelas, & Kim, 2004; Roberts & Lawton, 2001). “Interwoven and multi-layered narratives reflect complex lifeworlds and suggest that mothers’ understandings of their child’s disability are constantly open to renegotiation and flux” (Fisher & Goodley, 2007: 76). Many mothers are extremely invested in their mothering identities and want to continue caring for children with intellectual disability at home in conjunction with improvements in supports, resources, and relationships with professionals (Redmond & Richardson, 2003; Todd & Jones, 2003).
Fisher and Goodley (2007) explored the narratives of parents of children with disabilities in order to conceptualize notions of enabling care based on 25 in-depth interviews, accompanying stories, and ethnographic data. Their research developed three recurring, interlinked, and sometimes contradictory narratives within parents’ stories: the linear narrative (individual adjustment model of disability), the narrative of challenge (resistance to normative and oppressive interpretations of disability), and the philosophy of the present and becoming (embracing uncertainty with a sense of optimism and hopefulness). They found that parents developed counter-narratives which, at times, resisted linear life models and freed parents to enjoy their children as they were. They also asserted that parents were able to develop stories that were neither linear nor heroic, but present and becoming, and thus perceiving life “as an open book rather than as a concluding chapter” (Fisher & Goodley, 2007: 66).

Davis and Carter (2008) found that children’s social skills deficits were predictive of overall parenting stress, parent–child relationship problems, and distress for parents of toddlers with an autism spectrum disorder (ASD). Benson (2006) found that both severity of child’s symptoms associated with an ASD and parental stress proliferation significantly predicted parental depression, and that the relationship between child’s symptom severity and parental depression was partially mediated by parental stress proliferation. Pottie and Ingram (2008) and Pottie et al. (2009) evaluated the relationship between stress and daily affect among parents of children with an ASD. Using biweekly measures, the results of these studies showed that on days in which parents experienced higher levels of daily life stress they also reported greater negative affect. In addition, daily disruptive child behaviors were specifically associated with increased daily negative affect (Pottie et al., 2009).

In summary, many of the studies on the experience of parenting children with intellectual and developmental disabilities draw upon the stress and coping model, which have shown a correlational association between parental stress management and coping with the situation. However, research is lacking on understanding the qualitative experiences parents face and the challenges they encounter (both personal and social) in raising children with developmental disabilities and the strategy they adopt to mitigate those negative experiences.

**Methods**

**Participants Recruitment**

1 Benson (2006) selected 18 different symptoms, characteristics, or behaviors commonly observed in children with ASD, which are: receptive and expressive communication difficulties, hyperactivity, rapid mood swings, shrieking or screaming, tantrums, social withdrawal, lack of eye contact, self-stimulatory behaviors, repetitive behaviors, sadness or depression, sleep problems, difficulty adjusting to change, noncompliance, limited food preferences, pica, self-injury, and aggression towards others.
A purposive sampling method (Mayan, 2009: 62) was used to recruit the participants. I chose this method was because in my view only parents who have children with developmental disabilities would be able to provide ‘the best information’ (Mayan, 2009: 62) about the topic in this study. In October of 2010, I sent out requests asking for parents [whose children have been diagnosed with developmental disabilities] willing to be interviewed for this project, or if someone knew such a parent, he/she could refer that parent to me for an interview. In addition, I contacted several organizations (e.g., Family Support for Children with Disabilities [FSCD] program at Alberta Children and Youth Services, Alberta Association for Community Living, Alberta Association of Services For Children & Families, and The Centre for Autism Services Alberta), and sent them flyers to distribute among ‘potential willing-to-be-interviewed’ parents. I ensured that participation in the study would be voluntary, they could withdraw from the study anytime, and that their identity would remain confidential.

The study participants were selected based on the following criteria: (a) parents of children who are diagnosed with autism, ADHD, cerebral palsy, Down syndrome, and other types of developmental disabilities; (b) those children are under 18 years of age; and (c) equal preference for both Canadian and immigrant parents. Initially, seven participants who fulfilled those criteria responded to me by e-mail, expressing their interest in participating in the study. After receiving their e-mail, I sent them a consent form explaining the terms of participation in the study. However, two of them were unable to be interviewed because of geographic distance, and one of them withdrew consent after the interview was conducted; resulting in four participants. Upon receiving their consent, I asked each of them to inform me about a convenient time, date, and place for having the interviews. None of the participants received any remuneration.

**Meet the parents (and children)**

As illustrated in Table 1, parents in this study were three mothers (i.e., Nina, Joanna, and Romana) and one father (i.e., Jamal) of a child with a developmental disability. Two of them were Caucasian Canadian and the other two were Mexican and Chinese immigrants to Canada. Three out of the four parents had more than one child in the family, but for all parents, only one of their children had a developmental disability. Those parents ranged in age from mid-thirties to mid-forties and all spoke English. The age range of their children with developmental disabilities was between 4 and 16 years. During the interview it also came to light that one mother stayed at home and decided not to go for a job after her child was born, so as to spend more time with her child. Other three parents were working either full time or part time. Most of them had good family support, either from the spouse, children or from their relatives. The types of developmental disabilities of their children were autism, ADHD, global developmental delay, Prader–Willi syndrome, and non-specific learning disability. The children in the study consisted of three males and one female.
Table 1: Characteristics of the patents and their children

<table>
<thead>
<tr>
<th>Parent</th>
<th>Child’s disability</th>
<th>Child’s age</th>
<th>Diagnosis</th>
<th>Siblings</th>
<th>Immigration status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jamal</td>
<td>ADHD; high functioning autism</td>
<td>12</td>
<td>At age 3½</td>
<td>2; with no developmental disability</td>
<td>Canadian</td>
</tr>
<tr>
<td>Nina</td>
<td>Autism; global developmental delay</td>
<td>4½</td>
<td>At age 2</td>
<td>None</td>
<td>Immigrant (from Mexico)</td>
</tr>
<tr>
<td>Joanna</td>
<td>ADHD; non-specific learning disability</td>
<td>16</td>
<td>At age 7</td>
<td>2; with no developmental disability</td>
<td>Canadian</td>
</tr>
<tr>
<td>Romana</td>
<td>Prader–Willi syndrome</td>
<td>14</td>
<td>At age 2</td>
<td>1; with no developmental disability</td>
<td>Immigrant (from Hong Kong)</td>
</tr>
</tbody>
</table>

**Interviews**

In-depth interviews were conducted to listen to the stories (see Rapley, 2004; Miller & Crabtree, 2004) of four parents with a view to understand their experiences. I considered the interview data as a shared construction of reality by the interviewer and interviewee, or what Tim Rapley (2004: 16) calls “interview-data-as-topic.” The interviews were based on semi-structured (or focused) questions (Rubin & Rubin, 2005: 4) that I formulated, and thus, were open-ended. This was to encourage the participants to produce ‘thick descriptions’ or elaborated and detailed answers, rather than ‘yes-no-maybe’ types of responses (Rapley, 2004). The point was to follow the interviewee’s talk, to follow up on, and to work with them, and not strictly delimit the talk to predetermined agenda (Rapley, 2004: 18). Rubin and Rubin (2005: 14) used the term ‘conversational partner’ to designate the interviewee because the term highlights an active role of the interviewee in shaping the interview and guiding the research and implies a congenial and cooperative experience for attaining a shared understanding of the topic under discussion.

I prepared an interview guide consisting of several open ended ‘grand tour’ or main questions (Miller & Crabtree, 2004: 192-193), and within each ‘grand tour’ question, I organized some closed identifying or ‘mini-tour’ questions (Miller & Crabtree, 2004: 193) to follow up, probe, and further elaborate an issue if necessary. As the interviews continued, I used probes to
encourage the participants to further clarify or expand on the topic discussed or the issues raised. Those probes included not only ‘floating probes’ (e.g., silence, affirmative noise, recapitulation, etc.), but also ‘steering probes’ (e.g., continuation probes, elaboration probes, etc.) to further elucidate the discussion (see Miller & Crabtree, 2004: 191-194). The interviews did not involve both partners at the same time, because interviewing two people who are involved in an intimate relationship has inherent ethical and procedural challenges (Forbat & Henderson, 2003). A limitation of this study is the small number of participants interviewed.

Since most qualitative interviews are between strangers, the interviewing process requires establishing a rapport that ‘allows for an openness of exchange’ (Rubin & Rubin, 2005: 13), particularly at the initial stage. The participants were initially asked to ‘tell me a little bit about yourself and your family’, followed by ‘tell me about your child’s disability’. Further questions followed on the direction/nature of the answer to the initial question. As interviews progressed, I used more ‘probes’ and ‘follow-ups’ (Rubin & Rubin, 2005: 13) alongside the main questions. At the end of each interview, I asked the participants whether they wanted to talk about any issues that I did not specifically ask them about. Interviews were audio recorded and transcribed verbatim, and were not altered except for contextual clues indicated in brackets. Limited notes were taken so as not to detract from the flow of responses or conversation. Each interview lasted for about one hour. All participants were given pseudonyms to ensure confidentiality, and were offered a summary of the findings if they wanted information about the outcomes of the study.

One interesting dynamic impacting disclosure may have been that parents were willing to talk in great detail about their experiences of parenting a child with a developmental disability because the interviews provided them with an opportunity to ‘tell their stories’. In addition, they wanted to voice out their concerns, which can often produce ‘therapeutic’ results for themselves (Birch & Miller, 2000; Peddie, Porter, Teijlingen, & Bhattacharya, 2006; Shamai, 2003). At the end of an interview, one parent mentioned,

Nina: “When I read your e-mail [through listserv], I thought, well, this is my opportunity to say something about our cases. I hope your research will be beneficial to other parents who have kids with special-needs.”

Analysis

I used interpretive description as a methodological tool guiding this study. The purpose of interpretative description is to provide a conceptual description that contributes directly to our understanding of the experiences (Thorne, Kirkham, & O’Flynn-Magee, 2004), for instance, of parents who have children with a developmental disability. It involves the analytic processes that occur in transforming raw data into findings and in constructing an interpretive account of what the themes within data signify (Thorne et al., 2004). I did not search for previously set constructs, but rather I derived factors and dimensions presented as results from the stories of
parents by extracting what was most prominent in these particular interviews. I focused on the content and meaning as to what was being said, rather than on genre and narrative style. Coding categories were not established prior to the interviews but were identified during the process of transcribing and listening to the interviews. After reading the entire interview, I extracted relevant narrative units concerning each child’s disability and parenting, and organized them into different codes representing a particular aspect in the data. As Gibson and Brown (2009) mentioned, “[A] code is simply a conceptual device for the description of commonalities in data…” (p. 131). These codes are bundled together according to their clusters into a coherent thematic structure.

Initially, I ‘split-coded’ (Saldana, 2009) the interview data, and later I used ‘holistic coding’ (Saldana, 2009) to capture the meaning of an entire portion of an excerpt. Those holistic codes then were organized into multiple categories. Afterwards, those categories were organized into five major themes. During data analysis, I reviewed the transcribed interviews exhaustively for commonalities in the core experiences of parents and for shared perspectives on the interpretation and meaning of their experiences. In analyzing data, I used an emergent themes approach (Charmaz & Mitchell, 2007). They were based on the frequency and consistency of shared experiences or perspectives reported in the stories of parents. In addition, data were analyzed to yield topics that were most salient to those parents.

Findings

The performance of analysis resulted in five core themes, which included multiple sub-themes or categories within each theme. These emergent themes are: (1) negotiating joys and sorrows, (2) physical and mental exhaustion, (3) negotiating with family matters, (4) social stigma, and (5) hope in the midst of despair. The key aspects of those parents’ experiences are discussed below.

1. Negotiating Joys and Sorrows:

In this study, parents indicated that their experience of parenting a child with a developmental disability (DD) comprised both negative and positive aspects. Parents talked about their challenges and rewards of parenting a child with a DD, their expectations resulting in a sense of unfairness, and faith as a coping mechanism.

Challenges

The challenges of parenting a child with a DD constitute a salient theme across the four interviews. For instance, one mother (Romana) stated, “It has been a long journey for me.” The journey of parenting takes parents in both moments of joyfulness and grief. Going through their daily life, parents have to negotiate between the task of taking care of their children with a DD
properly and satisfaction that comes with accomplishing and fulfilling their role that results in becoming successful parents. Thus, in performing parenthood in the context of developmental disabilities of children parents go through ups and downs in life. This is illustrated succinctly by a mother:

   Joanna: “It’s really a roller coaster. Sometimes it’s intense, and full of anxiety, and um, very disheartening and very worrying. And other times, it’s just like any other kids…. [I]t kind of goes in cycles, I think.”

Having a child with a DD may pose exceptional challenges for parents. These challenges are acute particularly at the early stages of diagnosis, at which point parents may experience shock and lament. Parents in the study mentioned phrases such as “devastating,” “heart-breaking experience,” “bottom of the hill,” “too much,” “painful,” “guilty,” and “frustrating” to indicate their negative experiences in raising a child with a DD. As one parent stated,

   Jamal: “It’s very difficult. Very very difficult. Very challenging. At the same time [parenting is] very rewarding. Very difficult because you always have to, um, manage everything within the limited resources, right? … So, in order to meet those challenges, being parents, we are always on our toes, you know….The whole experience is tremendously challenging.”

The same parent also recalled:

   Jamal: “And parenting itself is challenging enough. But having kids with special condition, or autism, it is… I say it is, my son is equals to 70 children, you know.”

According to another parent,

   Nina: “It’s like… if you can imagine 10 times the challenge, it’s like that. I always say, being a parent is a challenge. And being a special-needs parent, is 10 times the challenge.”

Therefore, the challenge that comes with parenting a child with a DD is tremendous. As Lalvani (2008) asserted, it is a uniquely different experience that transforms parents’ expectations of parenthood as well as their definitions of normalcy. Many studies on caregiving children with developmental disabilities have focused on the negative impact of the experience on caregivers’ emotional lives (e.g., Heiman, 2002; Landsman, 2003). As parents in this study indicated, it requires several times more effort to take care, nurture, and fulfill the needs of those children. Due to these extra challenges, parents have to put more effort into a child with a DD compared to typically developing children in fulfilling their roles.
Rewards

Along with the challenges, raising a child with a DD comprises some benefits for parents as well. These rewards can manifest in the form of creating a positive outlook in life for parents. One parent illustrated how the experience helped him to gain patience,

Jamal: “[I]t is rewarding. He is also teaching us lots of things, like the immense patience… that probably you cannot beat me in patience anymore. Like you know, nobody can beat me in patience. You can throw any kind of challenge to me, and I’ll just be very very patient. Because he (the son) has taught me those kinds of patience.”

In this study, some parents indicated that their children with a DD also brought joys and happiness to them. For some parents, their child’s developmental disability taught them to be resilient in the face of challenges (e.g., “nobody can beat me in patience”). Parents also related the positive experiences and personal transformations that parenting the child brings about. Although parents have to face tremendous challenges in raising their children with a DD, this process assist them to look into the positive aspects of the experience. One parent has clarified,

Jamal: “[We] think more about the positives than negatives actually. Because he brings in lots of laughter, lots of joys in the family. And looking at him, um, he is special…. It is fun to have a child around. So we are very happy.”

Looking at the positive aspects, another mother recalls,

Romana: “I think the positive part is to make me more humane. Like to feel the pain of others, to feel the pain of the unfortunate people.”

Past research has indicated that being parent of a child with a DD is not a devastating experience as many might assume; but rather raising a child with a disability can be as fulfilling as raising a child without a disability (King, Scollon, Ramsey, & Williams, 2000). Green (2007) found that despite socio-structural constraints associated with caring for a child with complex needs, most mothers perceived valuable benefits in having a child with a disability. Other studies asserted that although parents reported psychological and somatic distress, physical exhaustion, social suffering, and economic disadvantage as consequences of mothering a child with a disability, the vast majority described the experience as richly rewarding (Beresford, 1996; Landsman, 2003; Redmond & Richardson, 2003). Some parents of children with disabilities identified benefits of their ongoing caregiving responsibilities as the development of reciprocal support relationships in which a child with a disability provides companionship and help with daily tasks (Green, 2007). However, it should be noted that parents’ experience can be context driven. For instance, child’s age may be a factor in the experience of challenges and rewards of parenting. As children grow up, parents may become more experienced in dealing with the disabilities.
**Religion/faith as a coping mechanism**

People’s religious beliefs can serve as a mechanism for coping with the challenges associated with raising a child with a DD. In this study, parents narrated stories of how they came to understand themselves and their child’s disability through the prism of religious beliefs. Common to many of these accounts were beliefs that the child with a DD was a blessing from God, sent to them for a purpose.

Nina: “Because I feel that I’m not like other mothers. So, I know that God has sent this special son to me, because if he were [born] to another family, maybe they wouldn’t care… So, maybe God chose me for a special kind of life. So, that helps me a lot when I’m almost giving up.”

Another parent stated,

Jamal: “Yeah, because our religion, we just go back to the Holy Book. A true believer will be tested by all kinds of things in the world, right? And we see this as a short term. And we still say ‘all praise to God’. And whatever God is testing us with, we just need to have patience. And one day… and that day, the judgment day or the hereafter, life in the hereafter will be better for us. And that’s what we believe in.”

For those parents, religious belief was one of the most important factors that helped them make sense of their child’s disability. As Jamal views it, child’s disability may have a ‘short term’ challenge, but can produce rewards in the long term. Interview studies that include questions about religion find that parents who are affiliated with a religious denomination or faith incorporate religious beliefs as a way to make sense of why disability happened to their children, what it means for their children and family, and its meaning in the larger world (Weisner, Beizer, & Stolze, 1991; Scorgie & Sobsey, 2000). For some families, religion provides another cultural model for interpreting childhood disability, though not necessarily to the exclusion of the medical or social model (Weisner et al., 1991).

**Expectation of normalcy vs. reality**

Parents in this study had to negotiate with their expectation of typically developing children vs. the reality of having a child with a DD. This was apparent for all parents regardless of whether they had only one child or had more than two children. One parent, who has two typically developing children and one child with a DD, has asserted,

Jamal: “[It was] like ‘oh, I can’t take it anymore, I wish I didn’t have him, I just had two ‘normal’ children that we have,’ you know. I wish, or we wish that he wasn’t born like that…. The expectation is like, you know, he will just grow up like ‘normal’. And it is extremely sad for us to see him growing up with special needs…. So, definitely we have
regrets about that. That we wish that he was ‘normal’. That he could continue and lead his life normally.”

Similarly, a mother, who has only one child with a DD, recalled,

Nina: “And there are some moments in your life that you realize that things are different for you. And you don’t know why, you don’t know if you did something wrong, you don’t know [whether] it was your fault, you don’t know if you’re bringing the child to live just a painful life. So, it’s really difficult to realize that it’s not what you were expecting for most of your life or at least 9 months…. So I think that’s the worst part when you realize or notice that it’s not what you were expecting, or you are different from the rest of the whole world.”

Parents had had the initial shock of taking responsibility for their children with a DD, which they did not expect to happen. Parents realized that their children were not going to be like typically developing children, which created a sense of burden in them. When parents realized that their experience was going to be different from that of other people and that they would have to endure “a painful life” for their children in the years to come, their dream shattered and it made them “extremely sad.” This expectation of normalcy may lead parents to experience a sense of guilt in them.

Parents may also experience the tendency of psychological non-acceptance of their child when they are born with a DD. According to one mother,

Romana: “It was extremely… um, what do you call a devastating experience. It was like, um, I couldn’t accept it, for I think about 6 years…. And then when she was 4 years old, she couldn’t speak clearly… by 4 she was mumbling. People couldn’t hear her, so we started the language therapy. And then we did extra work with her and extra things for her. So, it was a heart-breaking experience. Like I couldn’t accept it.”

Therefore, there was a clear disconnect between what parents expected vis-à-vis what they experienced in real life. This experience may create guilt, shame, denial, anger, and other negative emotions in them, for which they may find it difficult to accept their children with a DD. Previous studies have categorized general reactions of parents of children with developmental disabilities into three key factors (Kearney & Griffin, 2001; Sen & Yurtsever, 2007): primary reactions (e.g., shock, denial, suffering and depression), secondary reactions (e.g., feeling of guilt, indecision, anger, shame), and tertiary reactions (e.g., bargaining, acceptance and adaptation).

**Sense of unfairness**

During interviews, parents expressed a sense of unfairness as to why they became the ‘victim’ of having a child with a DD. This may be as a consequence of anger they feel due to
being different from other parents of children who are socially recognized as ‘normal’. Anger can also be a major obstacle to parents’ acceptance of their children with disabilities. Anger is generally seen in two ways (Sen & Yurtsever, 2007). In the first way, parents ask the question, “Why us?” The second type, however, is when anger is directed at someone who is not the source of the problem (e.g., anger directed at a child with a disability who is not accepted by society). One parent (Jamal) expressed his frustration and anger in saying: “Why me? Why us?, you know. Why not somebody else? Or why, why it has to happen [at all]?”

Sense of unfairness experienced by parents can also be directed to God. When parents compared their child to other typically developing children, they posed question to the creator as to why God has provided them with this challenge. As one mother illustrated,

Romana: “I am a person with religion. So, the many questions I asked [to God] were: why? Why does that happen to me? Did I do something wrong? ... And I even asked, um, when I see those little sparrows, they were all ‘normal’, jumping up and down. And I said, ‘Why? Why God? You make them perfect! But why my daughter is not [perfect]?”

In this case, Romana saw other creatures (i.e., sparrows) that have a ‘normal’ life, and questioned God why He had burdened her with a child with a DD. It should be noted that some parents may have a different experience in this regard. Parents who experience a sense of unfairness may also find solace in religion. As Romana again stated,

Romana: “And I remember another time I had a good friend, she gave birth to a healthy little girl. I went to the hospital to visit her. But I just rushed out of the hospital. There were many people congratulating her. I just rushed out of the hospital, crying, ‘why other people’s children are always perfect, [but] not mine?’ I was sick, you know, I was really sick. Then I remembered a passage [from the Bible] that I read a few days ago, it says like when a person buys a painting, he doesn’t know how much the picture would worth, right? And God just died on the cross. For the little girl, the newborn baby, and my daughter, He pays the same price. No matter whether she [the daughter] is able [bodied] or disabled. So it just dawn on me that to God my daughter is as perfect as, as worth as the others. So, I was at ease.”

**Appreciation of child’s personality**

Despite their experience of negative emotion associated with raising a child with a DD, parents tend to appreciate their children for who they are. All the parents in this study mentioned that regardless of what kind of situation their child was in, they appreciated the personality of their child. As one mother mentioned,

Romana: “To appreciate the beauty [in her], and [I was] inspired by her. Because she is a happy person. She has a lot of colors. I think emotionally, um, like I think she gave me a
lot of grey or dark colors. But because of the grey and dark [colors], the red, oranges, and the different colors just bring forth.”

Another parent stated,

Jamal: “[He is] very interesting, very amusing, very charming at the same time. So, um, in general you can define him simply as a very charming and with a great sense of humor sort of human being. He is always a wonderful thing to, um, to have around.”

Comparison to typically developing children

A common thread running across all the interviews is a tendency of parents to compare their children with a DD with other typically developing children in society. Parents of a typically developing child have the responsibility to meet the needs of and prepare an appropriate environment for their child’s healthy growth and development. Parents of a child with a disability, however, in addition to these responsibilities, are also burdened with additional responsibilities, such as teaching the child skills and doing physiotherapy. The narratives of comparison of their child to other typically developing children come from parents in this study; as one mother recalled,

Nina: “When he can reach a little, small goal, you feel like ‘wow’, it’s really wonderful, you know. It’s like [the feeling of] ‘normal’ parents. Because I have a sister and she has 2 ‘normal’ kids. So I can see for her [kids] something ‘normal’. For me, [achieving] every goal is just a blessing. I can say wow, it’s just… I can feel that it’s wonderful. And you can appreciate just small things in life.”

2. Physical and Mental Exhaustion:

Physical exhaustion

In taking care of their children, parents’ physical health was greatly affected. When asked about the effect of raising a child with a DD on their physical health, one mother, Nina, said: “Uff, it’s tremendous. It’s just tremendous. At night, I’m just exhausted. I’m really really tired.” In addition, parents’ psychological health had strong effect on their physical health. In maintaining the daily routine of their children with a DD (which in parents’ view was several times more demanding than raising a healthy child) parents became exhausted. Parents did not mention specific physical demands in raising a child with a DD, but did mention what those challenges felt like (e.g., “my son is equals to 70 children” or “imagine 10 times the challenge”). Some parents mentioned that they needed to take their child to use washroom, to bathe them, and carry the child to the 2nd floor of a building when the child is heavy. As one parent stated,
Nina: “And now if he doesn’t want to go up by himself, because we’re living in 2nd floor, I need to hold him. And now he’s 20 kg. So, it has been very demanding physically. And no matter if I’m tired or not, I need to change his diaper. But he is not a baby anymore, right? He’s 4½ years old. So, it’s been difficult.”

Another parent reiterated,

Romana: “Physically it’s very exhausting. Because for many years I couldn’t sleep at night…. I had many sleepless nights…. Until 2 years ago, I was overweight. I couldn’t take care of myself. I couldn’t sleep well. I was very tired. Very tired, physically.”

One parent elaborated the daily routine in taking care of his son:

Jamal: “He still needs to be prompted to dress up. … He cannot use the bathroom [and washroom] by himself. So we need to be there [for his washroom/bathroom use]. Putting cream on his body 3 – 4 times a day is extremely challenging. But we must do that to make sure that he [his skin] is not dry. Because he has eczema and skin conditions. And doing so, it is not easy, because he is always resisting… And then struggle continues, right? But then again, you somehow end up putting some cream on his body. But after you do, and if you think about the whole day scenario, starting from 7 in the morning, waking up and dressing up all the boys, and feeding them, and then sending them to school, and then coming back from school, again the same deal. Until they go to bed at 9 [at night], 8:30 or 9 o’clock. At the end of the day, we are totally physically done. You know, physically exhausted.”

Stress and psychological health demands

Raising a child with a DD takes toll on parents’ psychological health as well. In this study, parents indicated several factors that affected their mental health, including stress, anxiety, and depression. These are reflected in several parents’ statements:

Jamal: “So, mentally, sometimes it feels like very irritating, you know, sometimes very anxious. And frustrated. Um, negative, and stress about everything, you know.”

Joanna: “[C]ertainly I have stress and emotional stress and anxiety that goes with this….That can get pretty hard to bear….And it’s pretty overwhelming. It’s pretty stressful…. And eventually you’re going to see your health suffer from stress.”

Nina: “Because we knew that it wasn’t our fault, in my case as a mother. But [at the same time] I felt really guilty, really bad – it was really depressing, really sad. Because I thought that I was doing something wrong.”
Prior research indicated that parents of children with an autism spectrum disorder (ASD) consistently experience elevated levels of stress when compared to other types of disabilities (e.g., Abbeduto et al., 2004). Based on a daily diary methodology, Ekas and Whitman (2011) examined the adaptation to daily stress among 46 mothers of children (younger than 18 years of age) with an ASD. Their findings indicated that life stress and child stress each, after controlling for the effects of other variables, adversely affected the psychological health of those mothers. Ekas and Whitman (2011) also asserted the possibility that mothers experienced stressful events and high levels of negative affect in the morning, which continued through the day, and then they experienced positive affect towards the end of the day, when more family supports were available. However, Hastings and Taunt (2002) argued that parents have positive experiences with their children and that those experiences may protect parents against the effects of stress.

3. Negotiating with Family Matters:

Shift in parenting style

In order to raise a child with a DD, some parents had to change their style of parenting from traditional to a unique style in order to accommodate the needs of their child with a DD. A child with a DD requires more attention, care, learning skills, and additional therapies, among others. Therefore, traditional parenting style that applies to typically developing children may not be applicable to a child with a DD. This may require re-shaping parenting style to meet the needs of child more so than the needs of parents. As one parent asserted,

Jamal: “Having autistic children at home… So, yeah, we definitely have to shift from very traditional, you know, um, parenting style. Which is, you know, authoritative vs. authoritarian, or a combination of authoritative and authoritarian parenting styles… (pause) to extremely unique parenting style. Like you know, I really don’t know how to define that…. we had to change our style. Yeah, we had to accommodate our lifestyle accordingly.”

Spousal relations

Having a child with a DD may also have a negative effect on marital relationships. The birth of a child with a DD may cause tension as spouses might blame each other for their child’s disability. The care associated with raising a child with a disability can also place a significant emotional and financial strain on families. Therefore, greater understanding and collaboration among spouses are crucial in raising a child with a DD. One parent reiterated this issue,

Jamal: “Because, just to let you know, that according to the most recent statistics, 80% of the parents of all autistic children are divorced. So, this is just a scenario to let you know, that how much pressure it puts on personal relationships, spousal relationships. It’s
tremendous. It’s unbelievable. Either both of them, or in many cases, at least one of them
cannot take it anymore, right? So, they just, just absolutely leave the scenario. And it has
become a common scenario. But we are still surviving (chuckle), and nicely [so].”

Another parent recollected,

Joanna: “I think, you know, overall we have good family relationships. Like I think we
have a pretty constructive relationship with him. And my husband and I are really on the
same page about things like, you know, occasionally one of us would be more frustrated
than the other one. But you know, for the most part, I mean like 99.9% of the time, we
are on the same page. We share the responsibility…. so it’s really balanced.”

Thus, having a good family relationship helps maintain stability of the family and to provide the
necessary attention and care that a child with a DD requires. The association between childhood
disability and resident family relationships has been well documented (e.g., Hogan, Shandra, &
Msall, 2007; Sen & Yurtsever, 2007). Previous studies noted that children with disabilities are at
an increased likelihood of experiencing their parents’ divorce compared to children without
disability (Corman & Kaestner, 1992; Joesch & Smith, 1997; Mauldon, 1992). However, parents
interviewed in this study remained intact in their marital relationships.

**Sibling relations**

Having a child with a DD in a family may affect the psycho-social aspects of other
siblings. There is also a concern about the adverse influence it may have on well-being and life
experiences of other adolescent or adult family members (e.g., siblings and others) with
intellectual disabilities (Blacher & Hatton, 2007). A parent has illustrated the effect on sibling
relationships,

Jamal: “And siblings… the other two children are tremendously impacted by this
actually. Because they are very young [the autistic child is the oldest]. And they always
ask about why he [autistic child] does, um, act differently. Why he screams, why he yells,
why he doesn’t have any sense of public or private?, you know. Why? Then we have to
sit down with them. And, um, try to make them understand, or explain the entire scenario,
that he is different, that his brain functions differently than yours.”

Another parent pointed out,

Romana: “I think the sibling relationship, well, they like each other. But my son would
not have the ‘normal’ sibling experience…. He accepts her, but he doesn’t talk with her
that much….They do not argue. They don’t get into fights. She doesn’t have the
intellectual ability to comprehend what he is thinking. But emotionally, I think she is ok.
Like she talks, she’s expressive. They relate very well. But they don’t do things
together.”
**Time demands**

Taking care of a child with a DD requires more time demands for parents. In most cases, parents interviewed in this study reported that they had devoted more time to their children to the extent they lacked time for their spouses. For this reason, families may need to make changes in their social lives. One parent mentioned,

Romana: “I think like we were too much concentrating on the child that we didn’t have time for ourselves. When they were little, we just poured all our efforts and time into them…. But if I could go back, I would maybe have dinner with my husband more often. But like it was just I couldn’t do it. So, at some point, we were like don’t have time for each other.”

In addition, parents may have to adjust their time according to the needs of their child rather than the needs of their own. A parent illustrated,

Jamal: “…my son takes all our time, and energy. And in order to just to keep up with his demands, and behavioral expectations, it is sometimes too much. I mean we always have to adjust our schedules and our work, behavior, and everything according to his schedule. So if you think from that perspective, yes. Our style, our discipline, strategies and everything have changed significantly.”

However, for some parents, the emotional toll was more acute than the time demand,

Joanna: “[F]or me I found it more emotionally demanding than demanding time-wise…. I wish it was more about giving the time to it, because I feel like that was more concrete and we’d see some results from that.”

**4. Social stigma:**

Throughout the interviews, all parents mentioned that they were subjected to stereotypes and social stigma because their child had a DD. As illustrated by one parent,

Romana: “… we have friends who have kids with similar age. It hurts, at some point. It hurts that parents compare my kid doing to this and that. [Their kids] go to the kindergarten, the most prestigious kindergarten. But I can’t relate to them. I cannot talk about [my daughter’s] experience every time. I don’t want to be like grumbling mom, or crying mom every time. So, it does affect.”

**Blaming the victim**

In this study, some parents indicated that they had been the victim of blame as a result of having a child with a DD.
Nina: “And also there’s a lot of people who can just blame on the mother, you know. Like ‘she’s not a good mother’, ‘she’s doing this, she’s not doing that’, and things like that you can perceive. But honestly I don’t care. Because after all these years, I’ve experienced all types of comments that are hurting for me. Sometimes I don’t want to hear comments from people that don’t even know me, right?”

There are cultural factors associated with blaming the victim, as a Mexican-Canadian mother illustrated,

Nina: “[O]ne day, I remember, I went to a restaurant in Mexico, and my son was crying and crying and crying. He was having a temper tantrum. So, one person came to my table, and told me, you know what, um, “you need to take care of your son. Because one day your son is going to grow up, and he’s going to leave you, and you’re going to suffer.” And I was really upset at that time…So, it’s really difficult, because at that time you cannot explain all your background, all, um, the context. But you can explain that…‘he’s not dying, he’s safe, he’s ok’.”

A Chinese-Canadian parent stated:

Romana: “I think prejudice is everywhere. In the whole world. Especially in Chinese culture, because we believe that a child with disability has something to do with the parents. Like there is something wrong with the parents. That’s why the consequences [e.g., disability].”

There was also fear associated with taking a child with a DD to public places;

Nina: “It’s difficult because like when you go to a party, people start to ask, ‘he is 4½ years old, why is he still in diapers?’”. So things like, “why he doesn’t want to come to play with my son?” And sometime you just don’t want to explain to other people why, you know…. Because ‘it’s not your business’, you know.”

Existing research has indicated that mothers are more often implicated in, and considered responsible for, their children’s disabilities or illnesses (Gray, 2002; Landsman, 2003). Beliefs that children with severe disabilities remain ‘socially unproductive’ and are ‘burdensome for society’ may mean that parenting investments are often devalued (Ferguson, 2001; Landsman, 2003). The latter point is recollected by one parent,

Joanna: “We live in a society that is very focused on productivity. And wealth and the trap in success. And your fancy cars, and designer clothes, and your big giant house in the suburbs. And being the kind of person who would get you that. And I’m not sure that he is that kind of person…. But you know, our society is not kind to people who struggle for whatever reason. And blaming individuals in society, when they are not keeping up.”
Furthermore, Brett (2002) asserted that parents clearly expressed the cause of disability as related not to the nature of impairment but as due to the way disability is perceived by society. Consider an excerpt of conversation between two parents taken from Channel 4’s documentary, ‘Young, Autistic and Stagestruck’, in which parents illustrated how they perceived social stigma.

Sabina: You know what, I’ve lived my life apologizing for Mollie. And I’ve now realized I’m not gonna do that. Because why should I apologize for her? She does nothing wrong.

Sue: Yeah, I know. I mean, I can count the times even when he was quite small, you know, I’ve had people come up to me, women come up to me, I could almost take it if it was man, but when women come up to you and start saying, “can’t you do anything with that child? Can’t you shut him up? Don’t you see that he’s creating havoc?”, you know. And you’ve sort of felt it like saying, “oh, we’d see if you can do any better?”

Sabina: Oh, you know I’ve had that day in and day out all our life since Mollie was a baby. And that’s why a lot of autistic families become recluse and stay indoors all the time…

Sue: Yeah, absolutely. Because why would you wanna put yourself through that?

Sabina: Don’t people realize that autistic people and children can have a relationship [with others]?

Su: It is very difficult. It is very very hard to cope with.

Confronting with professionals and agencies

Parents in this study were subjected to stereotypes by social workers and agencies that are supposed to support parents of a child with a DD. As one parent said,

Nina: “I’m going to be honest with you. The social workers from the FSCD program, they feel that they have the power to give you money or not. So, sometimes you feel that you can do nothing…So, sometime I feel like they don’t see us as persons. They see us as numbers. And that’s not human.”

Another parent also recollected,

Joanna: “I took [my child] to the doctor, because he injured his arm. He fell and hurt his arm, which has nothing to do with his ADHD or learning disabilities. But the doctor treated him differently. He knew [about child’s condition], he’s the family doctor. So, he said, you know, like just making comments about ‘these kids’. What do you mean ‘these kids?’ Like anybody can fall and hurt their arm. So, there’s that labeling and patronizing that goes on even when it is irrelevant.”

However, one parent mentioned that he received good service from a provincial agency.
Jamal: “[T]he FSCD (family support for children with disabilities) in Alberta… They listen to me very well. So, for the last 8 years, I have received tremendous, um, you know help from the Alberta government. And we are grateful to them. In terms of community aids, or behavioral aids, they have spent thousands of dollars for this. Whenever I asked for something they gave me that.”

5: Hope in the midst of despair:

Parents interviewed in this study were generally not very positive about future expectations of their children, but again they expressed some hope that things were going to be alright for their children in the future. Perhaps the most common experience of parents in the interviews was their worry about child’s development as an adult in the future. Two parents interviewed asserted,

Joanna: “And as he grows up, we see him turning into, you know, he’s a teenager now. And we see him becoming sort of a young man. So, we feel like ok, he’s actually growing up, there’s some maturity, there may be some hope. But on the other hand, you know, we worry about the same things we ever did. Is he going to do well in school? Will he get where he needs to get [to]? To be, you know, not just an independent adult, but fulfilled adult. You know, a career interested. Something besides ‘pumping gas’, you know.”

Jamal: “And so, one thing bothers us all the time that he is growing up, and how he will be treated by the society, right? How he will lead his own life when we will not be around. As long as we are alive, he’s fine. But when we will not be around, he will not probably get the same kind of nurture and affection from the society.”

Clearly, parents were concerned about the future prospects of their children with a DD when they would grow up. They were worried about the kind of career their children with a DD would have, whether they would be able to live their life ‘independently’ or become dependent on society, most importantly, how society will treat them due to their disabled condition. Some parent may feel that they must live forever to take care of their children with a DD. This factor may be associated with negative experiences that parents of a child with a DD endure. However, one parent seemed to be reasonably hopeful for the future of her child,

Nina: “So, even though sometimes the future looks really, um, challenging, but I try to be positive. I say, ‘Ok, for my son to be happy, I need to be positive’. Now, for me being realistic, I want just, just to see my son happy. That’s it. If he can reach other goals, that would be great, fabulous, I mean, it would be really nice. But I’m not like demanding that aspect. I just want to see him really really happy. And I’m positive about the future, even though sometimes it seems really dark.”
Parents also mentioned the importance of shaping policies to provide more care for children with developmental disabilities. As one parent asserted,

Jamal: “Because autism is increasingly, alarmingly increasing, you know, among the families. It is 1 in every 20 children, they are saying. And before you know, very soon it will be 1 in every 8 children or 5 children. Just like if you open the door, and say hallo to 3 children, one of them would be autistic. And it (the rate) is increasing alarmingly. It is rapidly common. So, it is extremely beneficial if the social policy makers, they could look into that scenario, in order to make things more normal, for the parents of autistic children. And make them more productive in the society. Otherwise, it is a very dehumanizing experience, for the parents, without any government support.”

Discussion and conclusion

This study explored the experiences of parents raising a child with a developmental disability (DD). Data from the in-depth interviews revealed five broad themes. Overall, the findings of this study demonstrated the complexity around diverse experiences that parents gain while raising their child with a DD. For instance, religion was a coping mechanism for some parents but not for other parent. In addition, some parents asserted that they have learned patience from their children with a DD, while other parent thought that that notion was ‘phony’. Taken together, the findings indicated the individual and social-structural factors affecting the experiences of those parents. Individual factors such as psychological health, physical health, age of child and severity of disability result in personal challenges that parents face, which can be easier to mitigate. While structural factors, such as social stigma, issues around ethnicity and culture, as well as the class structure that affect parents in terms of social challenges that are usually beyond the control of individual parents to change. The stories of parents affirmed Davis’ (1997) assertion that “the ‘problem’ is not the person with disabilities; the problem is the way that normalcy is constructed to create the ‘problem of the disabled person’” (p. 9). Other studies suggested, however, that parents who hold positive attitudes toward raising a child with a disability were often pathologized as being unrealistic, failing to accept their ‘tragic’ circumstances or being ‘in denial’ of their children’s problems (Ferguson, 2001; Heiman, 2002; Landsman, 2003; McKeever & Miller, 2004).

In this study, parents mentioned how they negotiated between the burdens and pleasures of raising a child with a DD. Although their expectation of having a typically developing child resulted in anger, which culminated into a sense of unfairness, ultimately finding acceptance of the child ‘as he/she is’ and appreciation of child’s personality were the best ways to mitigate the challenges that they faced. Parents also asserted that they suffered tremendous amount of psychological stress and physical exhaustion as a result of taking care of their children with a
It should be noted that disruptive behaviors associated with a developmental disability, such as tantrums and obsessive compulsive behaviors, greatly increase both the emotional and physical demands on a family (Higgins, Bailey, & Pearce, 2005). Existing literature indicated an unusual stress impact on mothers where children had autism (Hastings et al., 2005; Sivberg, 2002). Brian Boyd (2002) noted that, “as a group, mothers of children with autism appear to be the most adversely affected (than parents of children with Down’s syndrome) by the stress-factors that result from rearing a child with a disability” (p. 208). Bromley, Hare, Davison, and Emerson (2004) noted that parents of children with autism had greater risks of serious psychological distress than did parents of children with other exceptionalities.

In my view, the extreme levels of stress may be connected with perceptions of social stigma as a structural factor affecting parents who were interviewed in this study. Previous studies indicated that stereotypes and stigma are prevalent in society against people who are affected by disabilities. Using modified labeling theory and utilizing a mixed methods approach that integrates quantitative analysis of survey data, qualitative analysis of interactive interviews and personal narrative, Green (2003) examined the experience of courtesy stigma in families of children with disabilities. She found that courtesy stigma was a complex phenomenon that became woven into the fabric of the lives of mothers of children with disabilities in subtle, but pervasive ways. Mothers of children with disabilities experienced similar negative attitudes toward people with disabilities held by others in their community. Her study also indicated that maternal distress was the result of both the objective burden of caring for a child with a disability, and the perception of negative public attitudes toward children with disabilities. In this study, one parent (Romana) indicated how she was unable to relate to her friends who have typically developing children because of fear that they would blame her for her child’s disability. Another parent, Nina, was also affected by the fact that other parents treated her like “she was not a good mother.” At the same time, parents interviewed in this study described their personal challenges in raising their child with a disability. Thus, parents were subjected to a dual burden of taking care of their child with a disability and simultaneously facing social stigma for their child’s disability.

The phrase ‘children with disabilities’ is often viewed in terms of children’s impairment, which can hinder identification of the social context in which they experience impairment and enable discriminatory ways in which society views disability (Brett, 2002). Clearly, the findings of this study showed that parents’ experiences are situated in the context of how they believe society will view and treat their child. For instance, Nina, a Mexican-Canadian mother, indicated how cultural context shaped the way she was perceived by people as an incapable mother who was not taking care of her son ‘properly’. Another parent, Romana, mentioned that her child’s disability was perceived as “something wrong with the parents.” These notions are similar to previous studies suggesting that parents are more often implicated in, and considered responsible for, their children’s disabilities (Gray, 2002; Landsman, 2003).
However, many parents believed that their parenting experience was a source of personal growth. Parents often say things like: “This experience has made me a lot stronger” (Green, 2007). However, another parent did not agree with such a statement. Such apparently contradictory responses may reflect the paradox of parenting a child with a DD in a profoundly ablest society where, as Landsman (2003, p. 1949) observed, “I love you as you are” and “I would do anything to change you” are equally valid parental sentiments. Parents experienced that they needed to have great family relationships for successful upbringing of their child. In addition, they might need to adjust their parenting style according to the needs of their child. These experiences within the family often affected spousal and sibling relationships negatively. The time demand was also an important factor for many parents.

Self-blame was also common among parents, particularly among mothers. Using a narrative-based feminist approach, Peters and Jackson (2009) found that mothers experienced their caring responsibility as overwhelming, there were widespread social stigma and rejection, and that they were not only blamed by others but they also blamed themselves. Lucie Lawrence’s (2008) discussion of the pressures brought to bear on parents of children with disabilities who dared to go out in public with their children echoes the stress felt by all parents in this study. Lawrence noted that, “public space presumes normalcy” (531) and talks of “the constant struggle of navigating public spaces” (536). This ‘navigation’ of the public domain was a factor in the lives of all parents who have children with disabilities, and many parents in this situation felt that their competency as parents was judged and often condemned (Kediye, Valeo, & Berman, 2009).

Some parents in this study noted religion as an important factor in managing the challenges of parenting a child with a DD. A study consisting of 80 focus groups and 30 individual in-depth interviews for male and female carers from four British South Asian communities showed that many carers accepted the birth of a child with a disability as a “gift” from God (Katbamna, Bhakta, Ahmad, Baker, & Parker, 2000). However, some felt punished by God for some misdeeds in a current or past life, and questioned God because of it (Katbamna et al., 2000). A study investigating the role of religion and its relation to caregivers who had a child with a DD found that all of them expressed a belief in a personal God. Content analysis of their narratives focused on three themes: religion as helping in the face of challenge and struggle, as providing meaning and a moral/ethical path to good, and as a source of hope and peace (Rogers-Dulan, 1998). In a state of need and emotional distress, parents and relatives may turn to religion to assuage their distressing feelings and to answer questions regarding the ultimate cause of their child’s disability (O’Hara & Bouras, 2007). Parents may use their beliefs as a way to make sense of why disability has happened to their child and to come to an understanding about themselves and their child’s impairments in a religious framework (Durà-Vilà, Dein, & Hodes, 2010). The birth may evoke positive attributions such as a child with an intellectual disability is a gift from God or a divine blessing (O’Hara & Bouras, 2007). Nevertheless, these beliefs do not eliminate the challenges and problems associated with taking care of a child with an intellectual disability (Skinner & Weisner, 2007).
Finally, parents in this study expressed their concern as well as hope for the future of their child with a DD. Parents wanted their voices to be heard, so that collective actions can be taken to mitigate the structural problems such as social stigma and lack of social support in raising their child with a disability. As one parent asserted,

Nina: “I can say that special-needs parents deserve the best. Because we sacrifice a lot of things… And also we deserve to be heard. Because when I read newspaper, nobody talks about our needs, about our necessities. And there’s just a few organizations who can help us. For example, I can see that for homeless people, there’s a lot of organizations to help. So, we need that kind of support in order to do our job. … I see a lot of people with special-needs children, they just give them up for adoption. And for me that’s terrible. So, I think we need to be heard. We deserve it. And also we are part of the society. And the rest of the society should understand that we are not bad parents. We just have different cases than the other families. So, I think that we deserve the best.”

There are several other points that can be noted. I noticed that children’s age difference had diverse effect on parenting experiences, as was the magnitude of symptom of a developmental disability. A parent with a younger child (less than 5 years of age) who was diagnosed with a DD experienced the challenges more so than parents whose child was older (over age 12). It can be that younger children require more demanding care, but having a child with a DD intensifies the situation, as apparent from the findings. One parent who has a child aged 16 with mild form of autism described having less frustration and less burden because her son has now grown up. The other thing to note was that differences in citizenship/nationality produced different parenting experiences. One parent, who was not a Canadian citizen, said that she was discriminated against raising her child with a DD in Canada.

Nina: “I’m facing lot of troubles. Even though my son is Canadian, but they are telling me that you’re not. So I need to fight every time. So I say, ‘ok, I’m not Canadian, but my son is; and the service is for him, not for me’.”

Limitations and Future research direction

This study was not without limitations. The participants in this study were parents of children with different types of disabilities indicating that there are differences in their experiences. However, despite their differences, there are many issues that parents face which are prevailing. Furthermore, I have interviewed parents who live with their spouses. The experiences of single parents would probably be much different and complex. For single parents, caregiving work constitutes a barrier to employment when they find their days disrupted by their children’s unpredictable needs, which can put employment in inflexible jobs at risk (London,
Scott, & Hunter, 2001), particularly the low-income single-mother families being at risk for material hardship (Leiter, Krauss, Anderson, & Wells, 2004).

In the future larger study, the number of participants can be increased. Furthermore, participation observation and other inclusive framework can be used in future studies. More importantly, a better focus in a larger research project in the future would be to explore culturally negotiated aspect of parenting children with developmental disabilities. As McGrath (2006) noted, little work has been conducted examining the impact on immigrant families parenting a child with developmental disabilities. In addition, the focus can be on certain age group (e.g., below 12) or certain aspect of a developmental disability (e.g., either autism or ADHD) rather than the loose use of the term ‘developmental disability’ in future projects.

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References


Green, S. E. (2007). “We’re tired, not sad”: Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*(1), 150-163.


