RESEARCH PAPER

“It’s not what you were expecting, but it’s still a beautiful journey”: the experience of mothers of children with Down syndrome

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Aim: The purpose of this study was to describe qualitatively the experience of parenting for mothers of a child with Down syndrome and to explore what if any was the role of spirituality and organized religion in this experience. Method: A homogenous sample of eight mothers of children between 7 and 12 years of age with Down syndrome was recruited through a population-based source of families of children with Down syndrome in Western Australia. In-depth interviews were used to explore the mother’s experience of parenting and to examine the role of spirituality and organized religion in their personal experience of mothering. Results: In this study, stressful life events recounted by the mothers included initial acceptance, developmental behaviour of the child, functionality of the child, health conditions and financial stress. Overall spirituality was described as a stronger and more dynamic source of support than organized religion in coping with stressors and life’s challenges associated with raising a child with Down syndrome. Conclusion: Findings from this study revealed that being a mother to a child with Down syndrome can best be described as a mosaic of experiences, emotions and a journey of self growth. Both spirituality and organized religion to a greater or lesser extent were useful in mediating stress and supporting mothers particularly during challenging life events in the course of their journey with their child with Down syndrome.

Keywords: Coping, Down syndrome, mothers, spirituality

Implications for Rehabilitation

- Being a mother to a child with Down syndrome has been described as a mosaic of experiences and emotions including a journey of self growth.
- The birth and diagnosis of a child with Down syndrome are most difficult and stressful experience for a mother.
- Supports such as family, friends, spirituality and religion can play a key role in helping mothers of children with Down syndrome cope.
- Health care providers need to understand the significance of holistic support systems for families with a child with Down syndrome.

Introduction

Being a parent has been described as a juxtaposition of experiences from joy to stress, particularly when facing the challenges of daily life [1]. Raising a child with an intellectual disability can present parents with additional challenges [2–4]. Higher instances of stress, anxiety and depression have been reported in parents of children with an intellectual disability than in parents of typically developing children [3,5]. A large body of research has highlighted that among parents of children with an intellectual disability, parental stress is greater for the parent who is the primary caregiver [6–8] the majority of whom are mothers [2,9–11]. Having a child with an intellectual disability requires adjustment to a new life role as a carer and adaptation to the needs of the child [2]. Changes such as modified work patterns and social relationships are all factors that influence stress and coping of new mothers [10,12].

Research examining the impact of having a child with an intellectual disability has focused on negative outcomes such as maternal stress and depression [2,8]. Among mothers of children with intellectual disability, maternal mental health is negatively impacted by the perception of low

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The overall experience of being a mother of a child with Down syndrome between 7 and 12 years of age was recruited through Down Syndrome NOW study, a population-based data source of families of children with Down syndrome living in Western Australia [22].

The interview guide, which was developed [23], explored the overall experience of being a mother of a child with Down syndrome, including participants’ thoughts and feelings at diagnosis, the impact of their experience on life expectations and their relationship with their child. It also included questions on what spiritually meant to them and the role of spirituality and personal beliefs in acceptance of their child at the time of diagnosis, birth and during their growth and development. Finally, there were questions on religious affiliation, if any, and if so the current role of organized religion in their lives and at salient points in their journey with their child with Down syndrome. A pilot interview was conducted to ensure that the objectives of the study were fulfilled and questions elicited relevant information. Individual in-depth face-to-face interviews were conducted with participants by the first author over a 4-week period. All interviews occurred at a place nominated by the participant, either at their home or work. Socio-demographic information was collected via a questionnaire prior to the interview.

As the topic of discussion was of a personal nature, it was essential to establish rapport and reassure confidentiality at the commencement of interviews. Written informed consent was obtained prior to any data collection. Interviews were digitally recorded and lasted between 30 and 80 minutes. A journal was used to record reflections on the interview process as well as observations such as the attitude and facial expressions of the participant [24].

Reflective journaling enabled the primary researcher to record her experiences, reflections, thoughts and feelings in relation to the research process. It was also used as a strategy to examine any personal assumptions and declare any biases in relation to the research topic. The researcher was not of the same religious or cultural background of any of the mothers interviewed; this allowed her to be objective during data collection and analysis. There were no children with Down syndrome in the primary researchers’ family; however, the researcher did work with children with developmental problems and delays. In addition to the reflective journal, the researcher used methods of bracketing to minimize the impact of personal bias on the research process [25]. Bracketing was maintained through reflexivity, preparation prior to interviews and post-analysis coding.

Following each interview, recorded material was transcribed verbatim and re-listened to ensure accuracy [26]. The transcribed data were then de-identified and pseudonyms were created for each participant to maintain and respect their confidentiality. Data management was assisted by the use of NVivo software [27]. The open coding method as described by Glaser and Strauss [28] was undertaken by the first author and allowed for naming and categorizing of data. The relationship between categories was then explored by all authors to identify and refine core concepts [29] from which emerged the major themes surrounding the experience of having a child with Down syndrome [30]. Credibility was enhanced through maintaining an audit trail, review of data analysis by an expert in the field of qualitative research and the use of a reflective journal [21,31]. The final research findings were discussed with one of the mothers as an interpretive member.
check. This was not undertaken with all participants due to the time demands.

**Findings**

Eight mothers of children with Down syndrome between the ages of 7 and 12 years were interviewed for this study. Mothers all self-identified as Australian and were from various socio-economic, educational, religious and spiritual backgrounds. Three worked full-time, three worked part-time, and two were stay-at-home mothers. The women’s ages at the birth of their child ranged from 25 to 40 years, and all children were diagnosed with Down syndrome postnatally. All women in this study were married or lived with their partner and seven of the eight had other children (range from one to four) without Down syndrome.

Analysis of interview transcripts revealed that seven core concepts described the overall experience of mothering a child with Down syndrome, these were then condensed to five overall themes: The journey begins; raising a child with Down syndrome; significant stressors; sources of support and outcomes of being a mother to a child with Down syndrome. Data analysis revealed that spirituality and religion for women in this study could be best conceptualized as a source of support.

**The journey begins: birth, diagnosis and acceptance**

For all the women in this study, their journey as a mother of a child with Down syndrome began at the birth of their child. All children in this study were diagnosed with Down syndrome postnatally, making the birth and diagnosis a combined experience. Five of the eight mothers had received some form of prenatal screening which had suggested a low likelihood of a Down syndrome baby, two of the mothers decided to forgo any form of prenatal screening due to religious beliefs, and one mother who had been categorized as a high risk for Down syndrome, had forgone further testing due to religious beliefs. All mothers agreed that they would have been more emotionally equipped to handle the diagnosis of their child had it been received prenatally. However, several mothers, including Jane a 37-year-old full-time working mother of three reflected that there were some benefits in not knowing their child’s condition prenatally:

> If we had known [about his diagnosis] early enough, we would’ve faced a difficult decision whether to terminate him or not. I’m very glad that we weren’t given that option because it would’ve been the biggest mistake of my life if I had. (Jane)

Several mothers valued the opportunity to have a normal pregnancy without the stress of monitoring by specialists:

> We didn’t know for sure. Which is probably the best way to, because I had a nice pregnancy. I didn’t have to go to specialists, obstetricians, and all that sort of stuff. (Betty)

For all mothers in this study, their most difficult and stressful experiences occurred at the time of the birth and diagnosis of their children. All mothers described the enormity of this experience and their emotional state during this time as grief stricken and overwhelmed. They described grieving the loss of the dreams they had during pregnancy, the loss of the child they had imagined and the fear of an unknown future. Betty a 47-year-old, full-time working mother described her fears as:

> Just dreadful grief. Extreme distress…it’s a whole different pathway. So tremendous grief when she was first born for my normal baby that I didn’t have. (Betty)

Receiving their child’s diagnosis of Down syndrome lead mothers to question “Why me?” and “What have I done wrong? What did we do to deserve this disabled child?” They questioned the meaning and purpose behind having a child with Down syndrome, one of the mother’s Hannah, a deeply religious and spiritual mother questioned: “My God, my God, why have you forsaken me?” and that is how I felt. I felt like God had forsaken me” (Hannah).

Overall, these mothers described their dissatisfaction with the approach of the medical professionals who delivered their child’s diagnosis. They felt that the medical staff were not emotionally equipped to handle such a task and were very blasé or clinical in their approach. Hannah, then aged 40, even felt that her doctor in some way blamed her for giving birth to a child with Down syndrome:

> [The Doctor] had very bad bedside manners … I felt like he was blaming me for the birth my child. He kept saying, “So you didn’t have a test did you? You didn’t have a test did you?”

Several mothers had received the diagnosis of Down syndrome in their partner’s absence. For these mothers, their anguish was compounded by their loneliness and the absence of immediate emotional and physical support at this difficult time. Leanne a mother of two, who at the age of 32 had her child with Down syndrome 10 years after the birth of her first child, expressed the trauma of this experience:

> I was told by the paediatrician, but he chose not to wait until I had my partner with me and told me by myself, so that was probably the most traumatic thing that’s ever happened to me, to go through that by myself.

For Jane, the isolation of her experience of her child being diagnosed with Down syndrome was reinforced by nursing staff, who instead of talking to her provided “support” by leaving pamphlets and booklets in her room.

> My baby was in intensive care and nurses wouldn’t talk to me but would leave things on my bed; [they] would leave a pamphlet underneath the cot about breastfeeding a baby with Down syndrome. No one actually talked to me … I think I’d rather had someone talk to me.

For mothers in this study, the first phase of their journey of parenting a child with Down syndrome related to their gaining acceptance of their child. The timing of this acceptance
consistency. For example, Britt, mother to William, described the necessity of being a mother to a child with Down syndrome and finding the beauty in their children. Carey a 46-year-old mother of three described her journey:

It's more like a puzzle, or maybe a mosaic. It's never really finished. It just takes time and its bit-by-bit – the emotions. I guess its finding contentment in where she's at and also seeing the beauty in her. (Carey)

Raising a child with Down syndrome

For mothers in this study, the experience of raising a child with Down syndrome was one of extremes – “It is an experience of highs and lows.” Mothers’ daily lives were polarized between frustrations and rewards, however the "Rewards [were] richer.” Raising their child was described as “99% joy and 1% grief for the child [they] didn't have.” The women described feeling pride in watching their child achieve, and heartbreak when they struggled. Jane described this experience:

Watching [Ben] achieve things, which other children take for granted, makes my heart almost burst out of its chest. I'm so proud of him. But at the same time it can be extremely frustrating and sad because at other times you're seeing your child not doing things that children of his age are doing. That is hard.

The women expressed that one of their greatest frustrations was observing the delay in their child's achievement of physical and emotional developmental milestones in comparison to their normally developing peers. They felt anxious as a result of not knowing when their child would reach these milestones. Leanne described her daughter Megan's developmental pathway:

All those normal milestones that a child has are not normal for her. They all happen at a different time, so it's not the same. You will go through months and months of her achieving all these wonderful things, you're really excited, and then you realise, hang on she's not going to be able to do that, or she can't do that, and there's triggers that will remind you of the things that aren't going to be.

However, despite the challenges and difficulties of parenting a child with Down syndrome, the women in this study could not imagine their life without their son or daughter and cherished the contribution their children had made to their lives:

[Elle] is easily the best thing that's ever happened to me, to the power of a thousand. Easily the best thing. (Betty)

Central to all the mothers’ experience of parenting a child with Down syndrome was the need to advocate for their child, particularly in relation to access to therapy. This was described as particularly problematic and time consuming given a service environment of rapid staff turnover and lack of program consistency. For example, Britt, mother to William, described her experience of therapy:

I would never say anything against Disabilities, but they are very pushed for time. They don’t have enough staff. The staff are always changing. We did have a very senior therapist who was very good, but in the end her load was so great she just couldn't take William anymore, and then we had one that was just out of university, and she really had no idea.

Significant stressors

The experience of having a child with Down syndrome was influenced by many factors (Figure 1). Patterns in the data revealed that the mothers' mental health was particularly impacted by their child's behavioural problems and health conditions, society's misconceptions of children with Down syndrome, work-life balance, schooling, future planning and financial status.

Children's behavioural problems

Coping with their child's behavioural problems was described by mothers as one of the most significant stressors in raising a child with Down syndrome. Occasions when their child hurt other children or younger siblings were described as exceptionally distressing:

I guess the stressful time is when Ben hurts other children, particularly his younger sister...You don't know if it's intentional or unintentional, or if he knows his own strength. He's 12. He's going through puberty. He's getting pretty strong. (Jane)

These behaviours were described as having a particularly negative impact on the mother's mental health and family relationships. Rita, a 35-year-old mother to Lilly, described how she felt Lilly's behaviour had changed her:

I'm way more anxious than I've ever been. I used to think that I was quite a laidback, easy going person, but I'm quite anxious as a result of Lilly's behaviours...Lilly’s had some behaviours when she's with other children. If we've been in close proximity, she touches, hits, lashes out.

The mothers described the sometimes aggressive and antisocial behaviour of their child with Down syndrome as resulting in the restriction of family outings, holidays and socializing:

Our life as a family outwardly has really been diminished...We don't go on picnics because Ben will just run. We don't go camping. He'd run. There are lots of things we don't do which I see other families doing which we really miss. (Jane)

Mothers often described reduced socialization as contributing to the social isolation of their family. They described being invited out by friends less frequently or finding social outings stressful and “not really worth all the effort.”

Health conditions

Mothers commonly described the realization that their child had multiple health conditions as a major stressor in their experience of being a mother to a child with Down syndrome. Six of the eight children were born with additional birth abnormalities, the most common of which were related to the heart (six requiring surgical intervention)
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followed by respiratory (two), and gastrointestinal problems (one).

The need for surgery early in their child’s life was described as particularly difficult. Mothers described coping with the dual stressors of their child’s diagnosis and surgery as a “roller coaster period” of depression and stress. Commonly the women described the first year of their child’s life as revolving around minor and major illness, hospital admissions, surgeries and doctor’s visits, as Hannah, mother to Sarah recounted:

Every week there was a different specialist to see. Sarah had [urinary tract infections], ear infections, and then the heart surgery, and the bowel surgery. So you’re always going to see specialists and things—it was my life. It was all I did.

Mothers also described the anguish of seeing their child in pain as a result of corrective surgery and not being able to help. One such mother, Britt, 42-year-old, full-time working mother of five, described her anguish:

He was released just still a newborn baby; only six weeks old and you couldn’t even put him up against you to pat him because here he was with this terribly sore chest, wired together and he’d scream. It was very traumatic. I spent a lot of time crying. I just couldn’t handle seeing my child suffer. (Britt)

Society’s misconceptions of children with Down Syndrome
Collectively the mothers expressed frustration at what they saw as the community’s misconceptions of children with Down syndrome. They recounted experiences of where people had stared at their child or made hurtful comments. Jane described how she felt when going into public with Ben:

Society’s expectations; the looks that we get, or he gets, and we both get, when we’re out together. I choose to ignore them. If they want to stare, or comment, or whatever, that’s their problem, not mine.

The mothers described receiving comments such as, “Oh, Down syndrome, they’re my favourite, they are all so happy”, and described people making assumptions about their child’s abilities: [People] put limitations on what she can do because she has Down syndrome (Robyn). The negative attitudes of work colleagues, family and friends were also described as hurtful. Mothers expressed frustration at people’s expression of views such as, “You have to be a special person to have a child with special needs,” or that their child was “A gift from God,” or “God only chooses special people to have these babies.” Family members and friends all reacted differently but often, they felt people found it hard to talk about their child, as if talking about their child with Down syndrome was a “taboo” or the “elephant in the room.”

Finding a work-life balance
For the six working mothers finding the balance among work, home duties, and time for their children and themselves was a daily challenge. “Juggling and trying to have too many balls in the air at the same time” (Leanne) often resulted in the mothers neglecting either themselves or their relationships with their husbands:

I’ve got a lot on with work and just finding that work-life balance is stressful. Unfortunately, if any relationship suffers it’s going to be between my husband and I, because sometimes at the end of the day I’m just tired. And I’m giving myself to my job, and to my children, and to my employer, and sort of...save a little bit for myself. (Jane)

Financial stress
For mothers in this study the financial stress of parenting resulted from the direct costs of therapy and the indirect cost
of having to reduce work commitments in order to meet the
needs of their children. While Leanne felt that early inter-
vention for Megan was important, financially it put a strain
on family resources: *Well it costs more money, you know, so
financial it's stressful.* Robyn, a 41-year-old pragmatic mother
of four, described how she had dropped from a high to a low
earning position so that she was able to take her daughter
Carin to the early intervention therapies: *I was in a very senior
position when I had [Carin] and I dropped I think $40,000 a
year to go to a previous level job.*

**Schooling**

Managing their child’s education needs was a significant source
of stress for these mothers. Finding a school able to meet their
child’s needs, provide a positive learning environment and
enable their child to succeed was challenging. Mothers had
varying experiences with schooling. While some found that
a special needs school was appropriate for their child, others felt
that segregation hindered their child’s learning and develop-
ment. Britt found that when attending a special needs school
her son developed anti-social behaviours which resulted in
her moving him to a mainstream school where he had to “fit
in” socially:

> Kids with Down syndrome are very good mimickers, he would hear
a badly disabled child on the other side of the passage wall scream-
ing and he would copy them … We had other kids in the class that
were quite violent. I did not want him violent… I wasn’t going to have
him in a situation where he could copy abnormal behaviour. So we
moved him to [a mainstream school].

Mainstream government schools were viewed favourably
by mothers not only for being financially accessible but as
having to be “more accountable” for the amount of support
they provided for children with special needs and as having
“to achieve certain things with them” (Betty).

**What does the future hold?**

Collectively, the mothers were concerned about their chil-
dren’s future, both in the short and longer term. Robyn
described how initially she was worried about the achieve-
ment of developmental milestones: *What her ability would
be and what level of support would she need?* Longer term
concerns were related to the anticipated transition for
formal school to post-school. Mothers expressed their
apprehension in relation to their children’s future ability to
negotiate the community independently and make complex
decisions in relation to every day situations such as taking
the bus or talking to strangers.

> The big stressor is her vulnerability to be able to problem solve and
make those more complex decisions on her own safety; things like
catching the bus and dealing with strangers. (Rita)

Hannah, described her aspirations for her child’s future,
based on the achievements of other individuals with Down
syndrome within the work force. She had read about people
with Down syndrome who had been employed in child care,
which had given her hope for the future of her child: *There
are people in Sydney who have Down syndrome who work in
law firms … and there’s a lady in Sydney with Down syndrome
who’s worked in child care for more than 20 years. All of the
mothers shared concerns about their child’s long-term future.
The reality that their children, because of their impairment,
would have restricted access to life experiences and roles was
a source of sadness: *He’ll never go to university. He’ll never
father, give me grandchildren. He is unlikely to marry and … it’s
sad that he’ll never have that.* (Jane)

Mothers also expressed their fears for the longer term in
relation to who would take over care of the child in the event
of their death, and what this would mean for their happiness.
Several mothers discussed how they had planned for a future
where they may not be able to care for their child.

> The thing that I worry about is [that] I’ll die before she does and
then I won’t be able to keep looking after her. It’s not that I won’t be
looking after her when I’m 80. It’s that I won’t be able to keep look-
ing after her after I die. (Betty)

**Sources of support**

Mothers’ discussions of sources of support in their experience
of parenting a child with Down syndrome highlighted that the
most important resources were their own personal spiritual-
ity, family supports, shared experiences of other mothers of
children with Down syndrome and personal coping strategies
(Figure 1).

**Mother’s definition of spirituality**

Overall, the women’s discussion of the role of spirituality in
supporting their mental health was highly individualized,
complex and intimate. Although the women shared the
experience of parenting a child with Down syndrome, their
descriptions of the role of spirituality varied widely, with
insights and reflections emerging from individual life experi-
ences. For example, Britt described her spirituality as a deep
connection or belief in a higher spiritual being and God:

> It is our link and beliefs in the Lord. We view the Lord as the one
who’s died for us and shed His blood, and through that we can be-
come free of our sins, and really, we can have a close relationship
with divine persons. You’re forever conscious of the spirits.

Others felt they believed in a higher being, but found it dif-
cult to make an existential judgement. For example, although
Leanne believed in a higher being, she was undecided about
what her beliefs were:

> I have always had a belief of something higher than me. I question
it constantly, but I definitely believe that what goes around comes
around. Karma … I haven’t quite worked out what it is that I believe
in, but I definitely do … I do think it makes me feel better that I have
something to hold onto I suppose.

Others saw their spirituality as grounded in their personal
beliefs or philosophy which motivated and guided their life
decisions.

> I suppose my personal beliefs are … that you try to be nice to people.
(Betty)
Regardless of their personal interpretation, mothers in this study described spiritual beliefs as providing support in their experience of being a mother to a child with Down syndrome.

**Personal spirituality as a support system**

Having a child with Down syndrome challenged each mother's spirituality. This challenge resulted in either a reaffirming and strengthening, or weakening and even rejection of religious beliefs.

I've had a God, I don't care if He thinks I'm special. I didn't ask for this child. I don't feel very special at all. (Robyn)

Mothers who held religious beliefs described their questioning of a God who let them suffer and experience depths of despair. Many mothers described feeling anger towards God for allowing them and their children to suffer: If he's so powerful, why does any child have difficulties? (Robyn)

Others, whose faith was reaffirmed by the birth of their child with Down syndrome had also experienced this anger, but described it as part of their process of acceptance. These mothers described their anger as transitory and at its strongest during the initial diagnosis period. Later, these mothers overcame their anger and were able to integrate their experience of being a mother to a child with Down syndrome with their personal spirituality.

You go through a cycle of being frustrated and angry. Angry at God, or whoever you want to call it. Maybe it is easier than being angry at the people around you, I don't know ... It just helps, it's almost like you go through a certain process. (Leanne)

Religious beliefs were particularly important for these mothers during the birth/diagnosis period and at times of high emotional stress such as when their child was seriously unwell or required surgery. Belief in a higher power was a source of hope, comfort and strength, and helped mothers to feel more in control during difficult life situations. Religious beliefs also helped to facilitate and shape acceptance.

It was part of God's plan; it was going to be Ok. And that probably helped a lot, that belief that we'd get through it, and you don't get given anything you can't handle. (Betty)

Five of the interviewed mothers did not subscribe to religious beliefs, but took a more self-reliant approach to spirituality. For these mothers, their spirituality was founded on their own personal beliefs, values and framework for living. Commonly, these beliefs were strengthened through their experience of having a child with Down syndrome. These mothers took a very pragmatic approach to life, and described focusing on the positives and not the negatives of their experience.

I just have my brain and my thinking. I suppose my personal beliefs are, I've taken a lot from religion. I think it's the personal philosophy that you try to be nice, you try to be nice to people. (Betty)

**Family supports**

Mothers in this study discussed the importance of support from their husbands and family. All women in this study were married and commonly described their husbands as important in supporting them spiritually and in times of emotional distress. Many discussed the importance of the support that came from having shared values and world view. Several described how when they were struggling their husbands were a "tower of strength" (Betty), or how their "easy-going nature" helped them to "go with the flow when [they had] their moments." (Robyn). Meeting the challenges of raising their child together, as a couple, supported these women emotionally and spirituality.

Support from family members, in particular the mother's parents, was central in sustaining the mental health of mothers in this study. Both the emotional and physical support provided by family members was described as important. Having someone with whom to talk to and share facilitated coping. The physical instrumental support of family was critical during the initial diagnosis/adjustment period and during times of crisis such as when their child was admitted to hospital. This physical support provided by family included respite from child care, cooking and cleaning.

My family; my parents and my two brothers are amazing and wonderful; very supportive. My mum in particular, my mum and dad will have [John] stay with them for days at a time, which is great because in a sense that's respite for [my husband] and I. This last week they had all three kids which was incredible, I didn't cook, we went out for dinner, went to movies, we slept in. It was amazing time. (Jane)

**Personal coping styles**

Mothers adopted many personal coping styles which were influenced by their spirituality, life experiences, background and spousal support. Patterns in the data revealed that mothers with a more pragmatic and optimistic approach to coping with life described lower levels of stress and anxiety that mothers with less pragmatic coping strategies. When confronting stressors or difficulties these women did not focus on the negatives, but rather took a solution-focused approach. Mantras such as "Staying positive" and "getting on with it" were adopted by these women.

I am a fairly realistic sort of person. We can't change it. She's here. She's not going anywhere. It's not going to be fixed... No one's going to come and take her away. We don't refuse offers of help but in terms of she's ours and she's our responsibility and we look after her so we make our own path through things. (Robyn)

**Inspirational resources**

Mothers drew strength from hearing about the experiences of other mothers of children with Down syndrome. Hearing...
their stories helped to normalize their experiences and gave them a frame of reference for managing life’s challenges.

I’ve got all the books written by mothers with children with Down syndrome and that’s been really good, reading about other mother’s experiences, talking to other mothers that I’ve met along the way has … really, really helped. (Jane)

In reflecting on their experiences eight of the mothers referred to a poem: “Welcome to Holland” [32] which helped them to cope during the initial diagnosis/birth experience. Welcome to Holland is a widely recognized poem written by a mother of a child with Down syndrome [32]. The poem was described by the mothers in this study as giving hope, helping them to change their perspective of their child and their experience.

[The poem Welcome to Holland] is talking about [how] you were expecting to have a trip to Italy and you wake up and you’re in Holland, and it’s like that … Holland’s a lovely place, but it’s not Italy. So you just have to get your expectations geared around a different situation. (Betty)

Down Syndrome WA

Mothers in this study found that the support and care provided during the initial period from organizations such as Down Syndrome WA were very useful. In particular, the mothers described the support of other mothers of children with Down syndrome as central in their coping during this early phase. These mothers were able to give them hope and provide a pathway through an unknown future.

I think the thing that I found most comforting was the mother that came around from the Down Syndrome [WA]. You know, she was attractive, she had her act together … Her life hadn’t fallen apart. So I thought that if having a child with Down syndrome hadn’t ruined her, you know? She was still really [normal], and I found that quite inspiring. (Betty)

Support from organized religion

Religious organizations provided emotional, instrumental and financial support to those mothers who sought help from their religious organization. However, mothers only received this help if they were part of a religious community. The mother’s involvement within an organization largely depended on the congregation’s acceptance of their child with Down syndrome.

Religious organizations were described as providing emotional support to mothers, particularly during the birth/diagnosis period. This support took the form of moral encouragement and prayers for the family: “they would come over and have a chat, and a cup of tea” (Britt). Mothers also found the instrumental support provided by their congregation important in reducing stress. During the birth/diagnosis period, church members dropped off cooked meals and/or helped with housework. Hannah recounted how her church had provided her family with financial support which had helped them through a difficult time.

Besides our church, we had two other churches supporting us, giving us money… They gave us a few weeks of frozen food. The other church took an offering and when we stood up and thanked them, they took another offering and they gave us $500 and it was enough to buy a fridge.

Outcomes of being a mother to a child with Down syndrome

Mothers described the many adjustments they had made as a result of their experience of having a child with Down syndrome. For all of the mothers in this study having a child with Down syndrome required a shift in life plans and routines. Many mothers mentioned a marked reduction in their number of friendships and social participation since the birth of their child with Down syndrome.

In general, mothers had found that having a child with Down syndrome had strengthened family relationships and brought their family closer together. Family members were described as very supportive and caring of each other and in particular of the child with Down syndrome. Some mothers also expressed the guilt that they experienced on behalf of their other children. They felt that the other children in their family had been deprived of individual attention and had to be more emotionally mature earlier. However, from these experiences mothers described the positive characteristics that their other children had developed due to having a sibling with Down syndrome. As Rita explained: I sort of felt bad. It is a big load on the other children but in a sense, it does them a world of good.

Mothers expressed that despite having a close family bond, they found that their relationships with their husbands were sometimes strained. The greatest challenge for mothers was having the time to focus on their marriage. Mothers found that children in general had a significant impact on spousal relationships, either reaffirming or weakening them. As Betty reflected:

I think babies will exacerbate whatever the relationship’s like. Like if it’s a big strong, solid relationship then babies will make it more solid, if it’s a shaky relationship then babies will make it more shaky.

Mothers in this study commonly felt that through their experience of being a mother of a child with Down syndrome they had grown as individuals and were more compassionate and accepting as a result. They felt that having a child with Down syndrome had contributed to their sense of self as a person and as a mother. Mothers had felt that their priorities in life had changed, that they were more grateful for small joys, and had learnt to be more relaxed and “not sweat the little things.” They felt that as a result of their experiences they were emotionally and spiritually stronger and had a clearer sense of their personal beliefs and values. Mothers with strong religious beliefs felt that through their life experience they had formed stronger links with God. Many mothers reflect that their life was certainly better for their child with Down syndrome being in it. As Leanne explained:

If you sort of look at it what’s happened over all the years, I definitely believe that [having a child with Down syndrome] made us better people.
Discussion

Overall, spirituality was described as a stronger and more dynamic source of support in coping with stressors and life's challenges associated with raising a child with an intellectual disability than organized religion. However, both were useful in mediating stress and supporting mental health particularly during stressful life events. In this study, stressful life events were described as initial acceptance, developmental behaviour of the child, functionality of the child, health conditions and financial stress.

Mothers in this study reported using some form of spirituality to cope with the acceptance of having a child with Down syndrome. However, there was a tendency for mothers to use their personal rather than their religious beliefs in coping as well as in understanding and making sense of disability. Mother's descriptions of personal beliefs were consistent with previous studies conducted by Fewell [20] or Haworth et al. [33]. As others have done [34,35], we also found that having a child with a disability caused individuals to question their personal beliefs, values and priorities in life.

In particular, mothers tended to question themselves and the universe. When considering religious beliefs and the notion of a higher being or God-like spirit who is the creator of life, individuals found it difficult to find the meaning behind having a child with a disability. The most frequently asked question was “Why?” and mothers commonly struggled with spiritual questions such as: “Why does God create disability?” Studies examining the use of spirituality or religion in coping with having a child with an intellectual disability consistently found that mothers frequently asked the question “Why” during the initial acceptance phase [20,34–36].

Overall, mothers highlighted that both personal and religious beliefs were an integral part of reaching acceptance. This finding is consistent with previous qualitative research Treloar [35], where mothers were shown to use their spirituality to guide their understanding of the difficulties they were experiencing, then to establish a meaning for disability and finally to facilitate acceptance. In general, it was found that hope and prayer were specific facets of spirituality which helped them in achieving acceptance.

Religious organizations provided instrumental and emotional support only to those mothers who actively sought help from their religious organization. Mothers in this study highlighted that the emotional support provided by their congregation and minister to be very beneficial in supporting their mental health. Research within the normative populations indicates that strong social support systems provided in religious settings are associated with better physical and mental health outcomes [37].

Additionally, Fewell [20], in examining the support provided by religious organizations, highlighted that they also provided social, educational and structural support. The provision of structural support at key points such as baptism or marriage helps individuals to adapt to new life roles and responsibilities as they progress through life [20]. Overall, mothers in this study viewed religious organizations as supportive, accepting and beneficial to families.

This study found that mothers' personal experiences of having a child with Down syndrome varied considerably and related to the circumstances of diagnosis, the child's current age and functionality and the support systems available. Research into this area showed that the timing and way in which the diagnosis of Down syndrome is delivered may influence the coping of mothers [38].

Mothers who had strong support systems from both spouses and immediate family reported better mental health. Considerable research has highlighted the importance of the role of social support and its role in mitigating stress and facilitating positive coping. Parents of children with intellectual disabilities who receive greater support have shown better psychological adjustment and positive coping [17].

Other avenues of support include personal experiences of other mothers of children with Down syndrome and the poem Welcome to Holland [32]. Mothers found that reading or listening to other mother's personal experience of having a child with Down syndrome was particularly useful. They could use this information as a point of reference in coping with stressors or coming to a greater acceptance to being a mother to a child with Down syndrome. The poem Welcome to Holland was a source of support and comfort or gaining perspective for mothers in coping with the initial diagnosis period and accepting their child [32]. The poem allowed for a paradigm shift in the perspective of having a child with Down syndrome; “it's not what you were expecting but it's still a beautiful journey” (quote from Betty).

Conclusion

The findings from our study and the paucity of previous research examining the role of spirituality in supporting the mental health of mothers of children with Down syndrome highlight the need for further research to be conducted. Results from this study can contribute to the understanding of spirituality and organized religion as a support mechanism to guide health professionals and service providers concerned with meeting the holistic needs of parents, families and children with Down syndrome. Ultimately the role of supports such as organized religion and spirituality may lead to enhanced well-being for mothers of children with disabilities.

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References


