

The Intersection of Societal Attitudes, Spirituality, and Parental Coping: A Study of Omani Families caring for Children with Disability

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Spiritual beliefs are highly valued in Omani society. However, there is a paucity of understanding on how these beliefs influence the experiences of parents who care for children with disabilities, particularly in terms of parental coping mechanisms. The spiritual perspective of parents may significantly influence their attitudes, actions, and emotional reactions, and therefore impact their approach to caregiving. This qualitative study explores the experiences of Omani parents of children with disabilities, investigating the effects of social attitudes such as ableism and stigma towards disability and its intersection with spirituality. Photo-voice and in-depth interviews were employed as the main methods. Participants captured images representing their spirituality, which were analysed along with interview transcripts using interpretive phenomenological analysis. Two main findings emerged: Omani parents of children with disability held negative perceptions of disability due to the negative interactions they encountered in their social circles as explored in the theme ‘the sick child’; and parents’ positive spiritual perceptions of their children worked as coping strategies- key aspects of the theme ‘my child is unique’. In conclusion, this study reveals a complex interplay between negative societal perceptions and positive personal beliefs among our many parents of children with disabilities. These findings suggest that while societal attitudes can adversely affect parents’ views of disability, fostering a supportive and spiritually enriching environment may enhance resilience and improve overall well-being for these families.

Keywords: parents; spirituality; stigma; social isolation; Oman

Introduction

Oman is a Middle eastern Arab country, with an estimated population of 4.9 million (NCSI, 2024). The prevalence of disability in 2024 is estimated to be 1.77% (NCSI, 2024). This figure is based on the number of individuals holding a ‘disability card’ issued by the Ministry of Social Development (MoSD), meaning that it does may not fully capture the total population of people with disabilities. The official religion of Oman is Islam (Al-Azri, 2013). Oman is considered a developing high-income country (World Bank, 2023).

In the last few decades, Oman has undergone rapid change. Oman's GDP per capita has increased steadily since the discovery of oil in 1964 and the beginning of exports in 1967 (Al-Azri, 2013). Like the economy, the healthcare system in Oman experienced rapid growth. While in 1970, the only medical care in Oman was offered through a missionary station in Mutrah, in Muscat, currently there are more than 71 hospitals and 190 health centres (NSCI, 2021).

The healthcare system in Oman, similar to that in other developing countries, is geared towards the eradication of infectious disease and the improvement of primary care (Al-Adawi et al., 2012; Alakhzami and Huang, 2020). This has led to reduced morbidity and mortality rates and increased life expectancy (The Ministry of Health (MOH), 2024). However, improvements in services for people with disabilities have lagged considerably (Alakhzami & Huang, 2020). The MOH is currently working on a vision for 2040 to address the demand for improved quality care for people with disabilities (MOH, 2024).

The 2020 census, which utilised data from the Ministry of Health and Ministry of Social Development showed that 57% of disabilities in Oman are caused by congenital abnormalities. The high rate of congenital anomalies in Oman is believed to be driven by cultural factors. For example, due to the tribal system, approximately 50% of marriages in Oman are consanguineous, of which almost half have first-degree consanguinity (Ministry of Health (MOH), 2014). Given the limited availability of services for children with disabilities and the central role of families in influencing the lives of Omanis, the primary responsibility for caregiving for children with disability largely falls upon the family, particularly on mothers (Albloushi et al., 2019).

Extensive research in the disability literature identified a number of challenges faced by parents of children with disability, including stress (Estes et al., 2013), financial barriers (Montes and Halterman, 2008; Pickard and Ingersoll, 2016), isolation and stigma (Crabtree, 2007; Nahal et al., 2017), lack of services (Pickard and Ingersoll, 2016; Masulani-Mwale et al., 2016) and unequal parenting (Ludlow, Skelly and Rohleder, 2012).

The literature indicates that spirituality may play a crucial role in parents' belief systems, with direct implications for their mental health (Pandya, 2018). Research has examined the connections between spirituality, resilience and coping strategies (Ekas, Whiteman & Shivers, 2009; Pandya, 2018). However, despite such research, defining spirituality remains challenging (Hill et al., 2000), largely due to diversity of cultural and religious contexts (Van Niekerk, 2018). Although numerous definitions of spirituality exist (see for example Zinnbauer, Pargament and Scott, 1999; Hill et al., 2000; Van Niekerk, 2018), this study conceptualizes parents' spirituality broadly, encompassing a worldview and sense of self rather than being confined to specific religious beliefs or value systems.

There is a significant lack of literature on the experience of Omani parents of children with disabilities and their spirituality; therefore, this study aims to explore the experience of Omani parents in raising a child with disability in Oman and their spirituality. This research article is part of a wider research project, the purpose of which is to understand the experiences and perspectives of Omani parents with children with disability, by investigating the effect of societal attitudes such as ableism and stigma towards disability. This research article focuses on the role of spirituality in parental coping and responses to disability and to analyse the intersection of cultural beliefs, spirituality and perceptions of disability.

Methodology

This study used a qualitative approach that emphasises the richness of the data, rather than its quantity or measurability. The research methodology for this study was based on interpretive phenomenological analysis (Smith et al., 2022). IPA was chosen because it facilitates an in-depth analysis of the parents' lived experiences. The spirituality of parents and their experiences in caring for their children was explored using photo-voice (visual data) and semi-structured interviews (verbal data).

Photovoice is a visual method based on participant-generated photography (Wang and Burris, 1997). It involves participants being introduced to the method, and then trained, before taking photographs themselves (Wang and Burris, 1997). After the photographs are taken, the participants engage in an interview to discuss the photos with the researcher. Etymologically, photovoice encompasses visual and verbal communication, which allows participants to communicate their realities visually. People in Oman, especially women, are not accustomed to expressing their opinions (Al-Azri, 2013). Therefore, the use of photos as medium was used to help participants express their thoughts and perceptions in a relaxed manner.

This section includes a description of the research procedures. The process included a training session, photo-taking task, interviews and analysis. Data collection was completed between February 2021 and December 2021.

The training session aimed to educate parents about the project's purpose, the ethics of photography and consent and training in basic photography. For the photo-taking task, the participants were asked to take pictures that reflected their spirituality. Participants were asked to take 5 to 15 images of things that represent their spirituality within two weeks, then choose three photographs and titles/captions they felt comfortable to share and discuss in the interviews. Participants were offered the choice of a face-to-face interview at the site where they were recruited or an online interview using Zoom. The interviews were semi-structured using an interview guide and lasted between 35 and 90 minutes. The interviews were recorded in an encrypted voice recorder and transcribed verbatim.

The study population was parents of children with disabilities attending the Rehabilitation

Department of the Royal Hospital or the Down Syndrome Association of Muscat, Oman. The inclusion criteria were: (a) mothers and fathers of children between 0 and 18 years of age who had a diagnosis of developmental delay or a diagnosis of any genetic disorder that causes developmental delay (for example Down's Syndrome). (b) Parents able to speak Arabic or English.

Eleven participants were recruited, ten from the hospital and one from the Down Syndrome Association (DSA). All participants were trained in the photovoice method and took 3 photographs each over a period of 2 weeks. All interviews were conducted face-to-face. All participants were married ($n = 11$) and working ($n = 8$) or stayed home to care for the children ($n=3$). The participants' demographic was composed of individuals classified as middle class or higher, with no participants representing lower socioeconomic status. The age range of the children was 0 to 15 years and the diagnoses included developmental disability. The findings reported here were derived from two sources of data: photographs (visual data, $n=7$) and interviews (verbal data ($n=11$)).

Data analysis

Photographs and interviews were analysed using the IPA process. Data analysis in IPA is an iterative and inductive process (Smith et al., 2009). This process aims to help develop an understanding of the perspectives of participants with an idiographic emphasis, focusing on individual experiences. Therefore, our analysis started with a focus at the individual level and moved to a more shared understanding as it progressed from a descriptive understanding to an interpretive one (Reid et al., 2005).

While there is no specific prescribed approach to data analysis in IPA research, we adapted the steps suggested by Smith et al. (2009) to conduct the individual analysis. After conducting the individual analysis, we created a 'profile' for each participant to provide an overview of their lived experience raising a child or children with disabilities and their spiritual beliefs. The themes emerged by looking across individual cases to find commonalities and divergences between them.

In the initial stages of analysis, we used NVivo 12 (2020); however, we decided to perform the second stage of analysis both manually and using Microsoft Word, as NVivo did not fully support the analysis process.

Ethical approval

Ethical approval was obtained from the Research Ethical Committee of the Ministry of Health of Oman and the University of Sheffield. Parents who were interested in being involved in the project were provided with an information pack that included information about the study and consent forms. To facilitate understanding, simple Arabic language, pictures, repetition of

information and bullet points were used. Informed consent was an ongoing process; before each meeting, participants were asked if they wanted to continue being involved and were reminded that it is their choice to be part of the project and that they could stop their involvement at any time. Anonymity was guaranteed to all participants. The identities of the participants are protected in written outputs by the use of pseudonyms. Aspects of the parents' and children's identities and characteristics have been altered to reduce the risk of their anonymity being compromised.

Findings

The key findings of this study revolve around two central themes related to the experiences and parents of children with disabilities and their spirituality. The first Theme, "The Sick Child", is primarily experiential and is firmly grounded in the interview data. It explores the concepts, beliefs, and attitudes toward disability, and highlights three main subthemes: understanding disability; experiencing disability stigma; and coping with stigma. The second theme "My Child Is Unique" consists mainly of the photo-voice findings, supplemented with interview data. It focuses on the spiritual perceptions of parents regarding their child's disability and encompasses two subthemes: transcending disability stigma through love; and supporting their children with disabilities to find their place in society. This theme delves into how parents use love to overcome stigma and actively help their children integrate and thrive within their communities.

Theme 1: 'The sick child': concepts, beliefs and attitudes toward disability

This theme describes the worldview of parents about their children's disabilities. Most parents (10) referred to the concept of 'normal' or *tabiei* to understand and describe their child's disability, with disability considered a deviation from normal/typical development.

Sub-theme 1: Understanding disability

This sub-theme explores four ways in which parents described disability: disability as the difference between 'normal' and 'abnormal'; disability as the difference between 'sick' and 'healthy'; disability as misfortune; and the rejection of difference. Parents said that their children's disability is what makes them 'different' or '*ghayr*' from typically developing children.

Latifa, a mother of four children with the youngest having a developmental delay, explained that she noticed that her daughter Al-Noor was different early on:

We noticed that Al-Noor was different since she was born. I mean, she is different from other children... So, I mean, thank God, when we noticed that she was different, we did not just sit and do nothing, we took her everywhere. (Latifa)

Latifa referred to her daughter's 'difference' with respect to the developmental delay that differentiates her from typically developing children, the identification of which accelerated their efforts to access therapy. Latifa continued to highlight the differences she perceives when she compared Al-Noor with her typically developing brother:

We noticed that Al-Noor showed slow development at every milestone... I tell you when she was born, even her eyes would not open... I mean for a month or so her eyes... I mean she was slow... did not open her eyes... similarly... I mean smiling... her smile was not like other kids... I mean even when you compare her to her brother, I mean he responded more and understands. (Latifa)

Here, Latifa engaged in social comparison as she noticed that Al-Noor was not as interactive or physically active as her brother. The perceived difference between Al-Noor and his peers was in the delayed achievement of milestones compared to typically developing children. Like Latifa, Shaikha highlighted her child's 'difference' from typically developing children. She found the parenting experience 'different' because her son Adam, a child with global developmental delay, needed close supervision and which placed intense demands on her:

I mean it is different from having a normal child... I mean you have to hold him... you must hold the toy... he does not have the strength to hold it by himself. (Latifa)

Shaikha is a young mother of a child with complex disabilities due to a genetic disorder, used the word 'different' to describe the parenting experience of caring for a child with disability, which implies that being 'the same' or caring for a typically developing child is more usual/normal. Shaikha gave an example of perceived difference:

He does not have the strength to hold [the toy] by himself.

Additionally, parents referred to their child with disability as *mareedh*, which is most closely translated as sick, referring to disability as a medical disease that needs to be fixed. When Shaikha introduced her children through a photograph she shared, she explained:

This child [pointing at the typically developing daughter] there is nothing wrong with her and this child [pointing at Adam] is sick. (Shaikha)

Shaikha described Adam as 'sick' or *mareedh*, a word in Arabic that serves several meanings: disease, deviation or deficiency. These meanings were reflected in the participant's discourses. The word 'sick' was used to refer to the child's disability, in contrast to using 'healthy' to describe her normally developing daughter. The term indicates that disability needs to be 'cured'.

Similarly, Al-Fajer, the father of a child with global developmental delay, spoke about the time the family learned about his son's disability:

We realised that Al-Amal is sick and has hypotonic nerves.

Al-Fajer referred to the medical cause of his son's disability by emphasising the medical explanation but shows a lack of accurate understanding of the cause of Al-Amal's disability. Nevertheless, his understanding of Al-Amal's disability seemed to encourage him to seek rehabilitation. It is important to note that it is common among Omanis to refer to hypotonia, decreased muscle tone, as 'hypotonic nerves', usually in reference to the medical care needed to treat it.

Unlike these participants, Samia, who has a daughter with physical disabilities, shared experiences completely devoid of terms such as 'abnormal' or 'sick'. Instead, she emphasized that her daughter's disability does not make her 'different' from other children, nor does it impose additional caregiving challenges, although her 8-year-old child needs help with all activities of daily living:

The challenges are just like the challenges with other children... it's the same.

However, during the interview, questions related to her daughter's disability brought up difficult feelings, as Samia cried heavily and was unable to share a detailed account of her lived experience and avoided discussing any challenges related to her daughter's disability. She explained that she found talking about her daughter's disability difficult:

Interviewer: Can you talk about it?

Samia: (crying) It's difficult.

The distress that Samia exhibited contrasted with her account that her experience was the same as that of any other parent. Shaikha, the parent of a genetic disorder, echoed this, she did not talk about her own child, but instead described a meeting with other people with Down syndrome as 'two poor people with Down syndrome.'

Sub-theme 2: Experiencing stigma

This sub-theme highlights the parents' experiences with disability stigma. The participants' accounts suggested that some people within their social circles, sometimes even close family, held negative views about disability, resulting in negative interactions and stigma, even from some healthcare professionals. The view of disability as a misfortune was also reflected in Sada's account. Sada, a medical professional and a parent of two children with developmental delay, described how her aunts attempted to support her emotionally because she is the mother of two children with developmental delays, however, they made her feel sad and frustrated instead. Sada explained that her aunts can be 'overly sympathetic':

They say: 'oh poor thing, she has two girls like this'... I mean I accept my situation and I continue to live... I do not live in sadness, so why do you bring me back to

sadness? Or sometimes they say 'poor thing' in front of a group of people... I mean sometimes an aunt would say 'may God ease it for you' and I feel it's okay to say it to me in person and when it's only us but when they say it in a group of people it makes me feel weak... I mean it's uncomfortable. (Sada)

By praying for her child in front of other people and calling her a 'poor thing' and asking God to make caring for her children easier, her aunts, though well meaning, made Sada feel sad and uncomfortable, as she was pitied in front of others. Being pitied by others also brought about difficult feelings for Latifa, as she felt 'weak', which may indicate that she felt humiliated or experienced a sense of inferiority.

The participants spoke about how other parents of disabled children in Oman approach their children. They explained that they found some children with disabilities within Omani society to be neglected by their parents, because they appeared to be uncared for or dressed badly, emphasising their 'difference' to typically developing children who were better cared for.

Al-Muthabira is a mother of seven, and her youngest son Mahboob has Down syndrome. She explained how some children with Down syndrome were neglected by their parents, which caused people to view them negatively. Therefore, she paid additional attention to her son's appearance and received compliments, even from medical health professionals:

Doctors everywhere say that Mahboob is well-presented. He looks stylish and all... even the doctor at the hospital says: 'You are different, glory be to God... some parents do not care about their children and they look messy... You give him confidence, dress him nicely, brush his hair... the child becomes confident. (Al-Muthabira)

These health professionals appeared to share Al-Muthabira's perception that parents sometimes neglect their disabled children by commenting that Mahboob was 'different' from other children with disabilities because he was well dressed. She described how health professionals attributed Mahboob's self-confidence to the care Al-Muthabira took in dressing him. Al-Muthabira was asked to elaborate on why she thought his appearance helped him with his confidence:

When he gets dressed, he goes and checks himself out in the mirror and all... yeah even in the optometry clinic, sometimes... that lady says (imitating) 'I like his outfit, I must take a picture' (laughs). (Al-Muthabira)

Zumuruda, a mother of three children and her youngest has developmental delay, made the connection between the lack of care given to the child and the parents' acceptance of their child's disability:

I mean I know children who are like Al-Amal but are not accepted... I mean they do not care about them as I care about Al-Amal... I see that their children are always dirty, I mean they do not care about the child's food, and all. I cannot think of a single day where I left Al-Amal dirty, I mean I change his outfits regularly... myself, the father and Shaima. (Zumuruda)

Here, Zumuruda explained that, unlike families that do not embrace and accept their child, she and the other family members made efforts to ensure that Al-Amal was cared for, prioritizing his cleanliness and appearance and assuming that keeping a child with disability clean and well-presented was a sign of parental acceptance of the child's disability.

The participants spoke about their perceptions of other people's beliefs about disability and how these perceptions influence how they interact with others and their children. Al-Fajer Zumuruda's husband, suggested that negative perceptions about disability held by people in society are deeply ingrained:

Some people show contempt for people with disabilities and neither I nor others can change it. These people exist whether we like it or not so I worry that people might look at him like this... I mean I worry that he will feel less of a person when an ignorant person looks at him like this or when a person who does not accept this group of people sees him... if a person looks at him with contempt, how will he feel? His disability is beyond his control. (Al-Fajer)

Al-Fajer's repetition of 'others' seems to signify that negative perceptions of people are difficult to alter. He appeared to be concerned about his son's feelings if he faced stigma from people in society. Although Al-Fajer believes that some people view people with disabilities as less than humans, he seemed to believe that this is unfair because:

...disability is beyond their control.

Participants continued to describe examples of their interactions with extended family members. Al-Shumookh, a mother of a child with Down Syndrome, mentioned that she has experienced stigma from some members of her extended family. Al-Shumookh used to take her son Al-Amal to all family gatherings until she learnt that some members of the extended family locked him outside their house:

...to be honest recently... they kicked him outside the house and locked him out.

When asked about her feelings, she replied:

What did I feel? Of course, it was painful... I mean you know this is my child... and they are not strangers... if they were strangers, I would make an excuse for them... I mean this is their child, you get me? What would I feel? Happy? I felt sad... I felt angry... I felt oppressed. (Al-Shumookh)

This encounter is full of negative feelings. Al-Shumookh seemed disappointed that her son was treated negatively, especially because family members initiated this behaviour, leading her to feel a combination of anger, sadness, pain, and oppression. However, Al-Shumookh decided not to confront her family members because she *'did not want to make it big'*, perhaps because she worried that confrontation would cause family conflicts and negatively influence family bonds that are highly valued in a collectivist society such as Oman. Instead, Al-Shumookh decided to limit her son's interaction with them:

Now I try not to let him visit them as much as I can.

These sentiments were echoed across accounts, where parents viewed stigmatisation as a barrier to social participation.

Sub-theme 3: Coping with disability stigma

Shaikha shared similar experiences when interacting with extended family members, as she felt judged and pressured when they commented on Adam's lack of physical development. Shaikha found that social restrictions due to the COVID-19 pandemic prevented her from being asked questions. She worried about the easing of social distancing restrictions because she will now have to face these questions again:

Even before the corona, I couldn't go out, because people ask. People keep staring at him I mean [mimicking people]: 'Oh we saw this child a couple of months ago and he is still the same'... society puts a lot of pressure on people. I even worry when the Corona ends, what will happen to me? They have not seen him for months. So now he will be 2 years old, they will see him, and he will be the same. (Shaikha)

Here, Shaikha expressed a fear of being judged, as she worried about future social interactions and the judgements people might make about her child's restricted growth. Shaikha appeared to be overwhelmed by the judgements people make about her child and her as the mother of a child with disability: '*society puts a lot of pressure*'. This pressures her to see the child achieve developmental milestones, which in Adam's case is challenging due to his global developmental delay.

Theme 2: 'My Child Is Unique': Parents' spiritual perceptions of their child with disabilities

Parents each shared seven photos that illustrated their spiritual understanding of their children's disability and their children's place in the social context. The photographs also caused a narrative change as parents spoke about their personal and spiritual understanding of disability, which somewhat challenged or rejected the traditional perspectives mentioned in theme 1. Parents spoke about how their spiritual perceptions of their children transcend the socially perceived 'differences' imposed by their disability. Additionally, parents discussed their spiritual beliefs about their social interactions and the place of their children in the world. The parents' spirituality seemed to be embedded in the parenting experience, as their spiritual perceptions shaped their relationship with their children. The parents' spiritual perceptions also influenced how they see their children with disability's relationships with their siblings and wider society. The spiritual perceptions parents shared appear to be positive, meaningful and hopeful.

Sub-theme 1: Transcending disability stigma through love

This Sub-theme details the spiritual values and beliefs of the parents reflect how they see their children. The parents appeared to see beyond their child's disability and emphasised their similarities to other children and shared hopes of integrating their children into society. To share his spiritual belief, Khalid, a father of a child with a developmental delay due to a genetic disorder, shared a photo he took of a heart-shaped lemon leaf (Photo 1).



Photo 1: The leaf: the only leaf that looks different from the other normal leaves in the lemon tree.

When asked to describe this picture, explained:

This is a lemon leaf that fell from a lemon tree and is different from the rest of the leaves... we judge it and say that it is sick or different... why is it not like the other leaves? But it has a unique appearance, a more beautiful and special appearance when you compare it to other leaves... for me, this leaf is like Mazin. I mean Mazin is the only child in the family who has this genetic disease and has a cousin who is normal, but I have Mazin and for me he is like this leaf... different but something substantial to me. (Khalid)

Khalid used this picture as a visual metaphor for his son Mazin. Khalid believes that people would generally label this leaf as 'different' due to its unusual appearance, indicating that

Khalid believes that societal views encourage viewing disability as an unwanted ‘*difference*’. He explained that ‘*we judge it*’, implying that he also has similar perceptions; however, since Khalid spoke about his spiritual beliefs while describing the photograph, he expressed this ‘*difference*’ in positive ways, as ‘*unique*’, ‘*beautiful*’ and ‘*special*’ or *mumayaz*. This had a positive influence on their father-son relationship, as Khalid described Mazin as ‘*different but something substantial to me*’, highlighting that Mazin’s disability does not lead to emotional distance - Khalid using the word *jawhari*, to describe Mazin’s position to him. *Jawhari* means substantial, essential, and intrinsic, indicating that Mazin holds a central place in Khalid’s life. Like Khalid, Shaikha also spoke about her perceptions of her child when she shared a photograph of her children smiling (Photo 2).



Photo 2: Happiness: The peak of my happiness is my children’s happiness.

The picture includes her typically developing daughter leaning towards her brother, Adam, who has developmental delay:

I mean, as a mother it does not differ for me. I mean, I just see their smile and it's enough for me. I mean, it does not differ for me that this child is sick and that this one is not. When they laugh, they are the same and they are my children. (Shaikha)

Shaikha stressed that Adam’s disability does not mean that his happiness or laughter is less valuable than that of his sister. Instead, Shaikha values and enjoys the happiness of both children equally, as she can see beyond his disability and enjoy his presence as her son rather than as a ‘*sick*’ child that needs additional care. Shaikha affirmed the sense that both children belong to her: ‘*they are my children*’, confirming that she perceives them similarly.

Abdullah, Sada’s husband and a father of two children with disability, also shared a photo of

his daughter Hadeel (photo 3). The image, taken by Abdullah on a family vacation to the beach, shows Hadeel smiling and playing.



Photo 3. My daughter: Keep your loved ones smiling as much as you can.

When asked to talk about the picture, Abdullah expressed his love for his daughter, although indirectly:

Hadeel is my daughter... every father loves his daughter, but this one... we went to the beach a couple of days ago and were playing... it's both play and exercise... physiotherapy I mean and play... we buried her legs in the sand and got her to exercise... we stayed there for almost an hour and she was laughing. (Abdullah)

Abdullah conveyed a powerful expression of emotion as he explained that 'every *father loves his daughter, but this one*', possibly indicating that it is normal for every father to love his daughter. However, '*but this one*' may suggest that his love for his daughter is special or that the moment he took the picture was special to him – it is more meaningful than the regular love a father has for his daughter. For Abdullah, making his loved ones happy, as her daughter, is a meaningful spiritual experience.

Sub-theme 2: Supporting their children with disability take their place in society

This sub-theme highlights the parents' love for their children and their hopes for their development and social relationships with their siblings and others. Zumuruda, a mother of three children, with the youngest having a developmental disability, appreciated the relationship her children developed, in which her older, typically developing children help their brother, Al-Amal. To share this, she took a picture of her children watching videos together. She also inserted flower icons beside her children (photo 4).



Photo 4. Love: siblings helping one another.

When asked to describe how this picture is spiritual, Zumuruda explained:

Interviewer: What does this picture tell us about your spirituality?

Zumuruda: Brotherhood first and the love amongst them... I love this picture because I lived in a loving environment... I mean we are connected and loving... I want my kids to grow up loving, the way I grew up with my brothers and sisters.

Zumuruda explained that Al-Amal's siblings are always eager to spend time with him and care for him and that she enjoys watching her children support and love each other. For Zumuruda, the relationship between the children is an outcome of love, which she sees as a spiritual bond.

Al-Shumookh shared a picture showing her sons, Al-Amal and Hamed, posing (photo 5). The photo was taken by Al-Shumookh when Cyclone Shaheen hit Oman in October 2021. In the picture, Hamed, a 6-year-old typically developing child, is standing behind Al-Amal while holding his brother's shoulders.



Photo 5: Brother: take my hand for you are my support.

Al-Shumookh likes this picture because she believes that the way Hamed is standing and holding Al-Amal signifies his support:

I chose it because I consider Hamed as a supportive brother for Al-Amal Al-Mutajadid... I see in Hamed an extension of myself and their father... I mean after us... this is what I hope... that Hamed will look after Al-Amal Al-Mutajadid... I mean see the picture (pointing at the picture)... Hamed is standing behind Al-Amal Al-Mutajadid and holds his shoulder as if he is saying to him 'I'm here Al-Amal Al-Mutajadid, and as long as I'm here, you're safe'. (Al-Shumookh)

Al-Shumookh described her youngest son, Hamed, who is typically developing, as an 'extension' of the parents. She said that 'after us', or *baadna*, Hamed is Al-Amal's 'support'. 'After us' can indicate that Hamed has been designated as a caregiver after the parents pass away or that he is second in the caregiving role. When asked why she chose this photograph to represent her spirituality, Al-Shumookh explained:

I believe that maybe God gave me Hamed after Al-Amal, so he supports and helps Al-Amal... to be close to him and for Al-Amal to find someone to care for him.

Al-Shumookh appeared to believe that Hamed's role was determined by God, placing significant responsibilities on him.

The spiritual reflections of Al-Muthabira and Al-Shumookh encompass the view of the wider society of people with disabilities. To illustrate this, Al-Muthabira shared a picture taken by Mahboob's sister (photo 6).



Photo 6: Stop lying, hating and envying. Stop calling us Mongolian. Stop negativity.

According to Al-Muthabira, the black and white picture shows Mahboob looking uncomfortable and trying to stop his sister from taking the picture. Later, his sister wrote the word 'stop' above him to send a message, the picture reflected Mahboob saying '*stop lying, hating and envying.*' Stop calling us Mongolian. Stop negativity'. Al-Muthabira wanted to share this picture as she believes that '*love*' can eradicate stigma and bullying.

Similarly, Al-Shumookh shared a picture showing Al-Amal sitting outdoors in a chair and sipping coffee (photo 7). The picture was taken when Al-Amal, his typically developing brother, his father, and some family members went on a three-day camping trip in Al-Ashkhara, a coastal fishing town.

The mother loves this picture because '*it has authenticity... it has some Omani values*'. When asked about how this photograph represented her spirituality, Al-Shumookh explained the following:

I love for Al-Amal to be like his siblings... Just as I instil certain values in them, I do the same with him... for example, the coffee, sitting confidently... you know how they say 'you are a man, when you sit, sit properly, do not wiggle' (Al-Shumookh)



Photo 7: Oman is my identity and I'm proud of its traditions.

Al-Shumookh appeared to be proud that her son was sitting in a culturally acceptable way. In Oman, when the phrase 'you are a man' is used, it usually refers to the traditionally accepted way of sitting where men are expected to sit still. In contrast, it is acceptable for women to move while sitting, therefore, when Al-Shumookh said '*you are a man*', he was referring to the traditionally accepted way of sitting, as a man rather than a child. Al-Shumookh views the cultural values she encourages her son to follow as part of her spirituality, which relates to the belief that adhering to societal norms and cultural values can allow Al-Amal to integrate and be part of the larger Omani society despite his disability.

Participants shared their spiritual perceptions of their children. In this theme, parents' spirituality appeared to be embedded in the parenting experience, as their spiritual perceptions shaped their relationship with their children. Parents' spiritual perceptions also influenced how they view their children with disabilities' relationships with their siblings and the wider society. The spiritual perceptions shared by the parents appear to be positive, meaningful, and hopeful.

Discussion

In this study, a group of Omani parents of children with disability shared their experience with caring for a child with disability. The study yielded significant findings regarding parental perceptions as they often adopted discourses around illness, abnormality, and grief to describe their child's condition, echoing broader social attitudes toward disability. The parents also shared spiritual perspective and personal beliefs that diverge from the prevailing societal perspectives on disability and tend to be more positive.

Research exploring the lived experience of parents of children with disability in Arab countries shows that parents frequently experience stigma (Crabtree, 2007; Nahal et al., 2017). Omani parents raising a child with disability face comparable challenges in this respect. The stigma experienced by Omani parents is multifaceted, originating from strangers, close family members and occasionally health professionals. This stigma, combined with the lack of resources, further exacerbates the caregiving burden for families raising a child with disability in Oman.

While extended family members in this study exhibited pity for the parents, some extended family members were violent towards children with disability. This finding supports the findings of other studies conducted among Arab mothers (Madi et al., 2019; Lamba et al., 2022), highlighting the need to address stigma within family contexts. Goodley and Runswick-Cole (2011) examined the multi-faced nature of violence experienced by children with disability in the United Kingdom. The findings showed an inclination for violence against children with disability rooted in the relationships, institutions and cultural acts. The authors explained that there is a need to reform and deconstruct the cultural norms that legitimise violence against people of disability (Goodley and Runswick-Cole. 2011).

Interestingly, all of the parents in this study who experienced stigma from extended family members decided not to confront them. This could be due to the fact that Oman has a strong extended family culture (Al-Barwani and Albeely, 2007). The extended family generally provides help and support (Al Busaidy and Borthwick, 2012). This could be due to socio-cultural norms common in collectivist cultures that prioritise maintaining reputation as 'a good group member' by avoiding conflict (Gelfand et al., 2012). In light of the lack of formal support services (Al-Adawi et al., 2013; Al Busaidy and Borthwick, 2012), parents may have chosen to cope with the emotional distress without confronting their extended family members, worrying that this would negatively influence their relationship with extended family and potentially limit the help they received.

Parents also noted that others often expressed pity for people with disabilities, viewing them as 'poor people' and presenting disability as a tragedy or disadvantage. Such attitudes reflect an ableist perspective, which equates normalcy with able-bodiedness (Campbell, 2009). These

ableist views, can perpetuate negative outcomes for disabled individuals and their families, leading to a pursuit of 'normality' at the expense of acceptance and inclusion (Slater and Chapman, 2015). These ableist views, can perpetuate negative outcomes for disabled individuals and their families, leading to a pursuit of 'normality' at the expense of acceptance and inclusion (Slater and Chapman, 2015). Parents in this study expressed a desire for their children to lead 'normal' lives, echoing Crabtree (2007) findings and indicating the widespread influence of ableist norms.

In this study, the way in which children were looked after and dressed, was linked to disability. For example, Al-Muthabira and Zumuruda noted that other parents of disabled children neglect their children by not providing basic care, such as keeping them clean, and emphasized that this accentuated the children's 'difference'. This was strongly conveyed in interviews with Zumuruda and Al-Shumookh, who, along with other members of their nuclear family, made extra efforts to dress their children nicely and keep them clean. This finding is consistent with that of McKeever and Miller (2004), who found that Canadian mothers of children with disability took great efforts to dress their children fashionably or in new clothes in order to deemphasize their disability. In this study, it appeared that some parents colluded with an ableist agenda and attempted to make their children appear less disabled or less 'different' maybe to protect themselves and their children from stigma.

The study also explored the role of spirituality in shaping parents' perceptions of their child's disability. A notable contrast emerges between the discourse in theme 1, which reflects the prevailing cultural narratives, and theme 2, where parents expressed their spiritual perceptions through photo-voice representations. Although the former often aligns with negative societal attitudes toward disability, the latter conveys more positive perspectives, reflecting a duality in parental attitudes. This duality suggests that parents may hold implicit negative attitudes influenced by societal narratives along with explicit positive attitudes shaped by their spiritual beliefs.

In order to draw conclusions about the nature of the positive perceptions shared by parents of children with disabilities, Hastings et al. (2002) argued that these parents do not merely identify positive aspects of having a child with a disability, but the positives they describe are examples of adaptive coping mechanisms via which they engage in positive reframing- a component of meaning-focused coping or meaning making (cognitive coping) (Hastings et al., 2002; Beighton and Wills, 2019). Positive reframing or positive reappraisal may help a person experiencing stress to reframe a situation in order to view it in a more positive light, which may be especially important in helping people sustain efforts (including caregiving) long term (Folkman and Moskowitz, 2000). In quantitative studies, positive reappraisal was found to be a significant independent predictor of positive perceptions for mothers of children with disabilities (Hastings et al., 2002). In addition, Beighton et al. (2017) conducted a qualitative study to explore the nature of positive perceptions of parents of children with intellectual

disabilities and concluded that these positive aspects are largely based on meaning-focused coping.

This study has expanded understanding of the spirituality of parents of children with disabilities and how the parents' spirituality is enacted in their parental role (affecting their behaviour) in terms of seeking rehabilitation services. Furthermore, while hope, optimism and self-efficacy have been explored in previous studies concerning parents of children with disabilities (Harty, Engel and Hohlfeld, 2018; Kozachuk, Wheeler and Carr, 2022), these aspects have not been explored thoroughly as part of spirituality. The findings from this study can be used to help understand how the spirituality of parents of children with disabilities can support positive thinking and parental well-being.

A growing body of evidence affirms the positive contributions of spirituality to well-being and quality of life for people with chronic illness (Bartlett et al., 2003; Riley et al., 1998; Saadah et al., 2014). However, the intersectionality of disability and spirituality is an under-researched topic. The majority of existing studies that explore spirituality and disability look at the religious dimension of spirituality (Bryant et al., 2011; Nario-Redmond, Kemerling and Silverman, 2019; Salkas et al., 2016), rather than encompassing a wider definition of spirituality. The limited existing literature on religion and disability stems mainly from Christian theology and ethics (Imhoff, 2017; Park, 2005; Stauner, Exline and Pargament, 2016), with scarce references to broader religious studies in disability literature.

Interestingly, parents often described their experiences of parenting a child with disability in positive terms, highlighting feelings of love, compassion, and connection. Such positive perceptions may not only strengthen the parent-child relationship, but also serve as coping mechanisms, buffering the stress associated with caregiving and promoting family well-being. The findings of this study align with research that shows the importance of positive re-framing or meaning-focused coping strategies among parents of children with disabilities (Hastings et al., 2002; Beighton et al., 2017).

Additionally, this study suggests a possible link between spirituality, positive reflection, and improved mental health outcomes among parents of disabled children. By reframing their perceptions through spiritual beliefs, parents can cultivate resilience and find meaning in their caregiving experiences, despite experiencing difficulties and stigma from others. Future research should explore this connection further, investigating how spirituality influences coping strategies and well-being among this population.

Clinical implications

There is growing recognition regarding the integration of spirituality and spiritual care in rehabilitation in general (Jones et al., 2022) and in occupational therapy specifically (Mthembu,

Wegner and Roman, 2018). This study adds to the existing body of knowledge as it sheds light on the spirituality of parents of children with disability and how it influences their lived experience.

For healthcare professionals working with parents of children with disabilities, gaining an understanding of parents' spirituality, can offer important insights when assessing the child or offering interventions for these parents. The period of rehabilitation may be a pivotal time for parents of children with disabilities to adjust to the diagnosis (Jones et al., 2022). The findings of the current study show that spirituality helped parents in the meaning-making process and facilitated positive reappraisals of the child's disability. Parents of newly diagnosed children have many years of meaning-making ahead of them. Therefore, training for health professionals on delivering disability diagnosis, compassionate care, offering information and ongoing support to parents and extended family can help the parents in the meaning-making process.

Conclusions

This study underscores the complex interplay between societal attitudes, spirituality, and parental perceptions of disability. The findings reveal that Omani parents face multifaceted stigma from various sources including strangers, family members, and health professionals. The stigma, compounded by limited resources, significantly intensifies the caregiving burden. Despite these challenges, parents often resort to positive re-framing as a part of their spiritual beliefs as a means of coping.

The study underscores the critical need to address stigma within family contexts, echoing findings from other Arab contexts and broader literature on disability. The stigma, and sometimes violence, reported by extended family members emphasizes the necessity for cultural and institutional reforms to combat such issues. The reluctance of parents to confront stigma from extended family members highlights the influence of strong familial ties and socio-cultural norms in Oman, where maintaining relationships is prioritized. This may perpetuate the status quo of ableism and stigmatization surrounding disability.

Moreover, this research adds to the growing body of literature on the positive role of spirituality and enhancing parental well-being and coping strategies. It reveals that spirituality can offer a framework for positive re framing, contributing to improved mental health outcomes and resilience. Future research should delve deeper into how spirituality interacts with coping mechanisms and influences the overall well-being of parents of children with disabilities.

Limitations

It is important to note that the participants in this study included parents caring for children

with disabilities caused by a diverse range of genetic disorders. Additionally, the majority of parents recruited in this study had pre-school aged children with disabilities as it was challenging to recruit older children. Future research should focus on specific disabilities to better illuminate the unique challenges, needs and adaptations associated with it.

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