

CAREGIVER EXPERIENCES OF CARING FOR A DOWN SYNDROME CHILD IN SAUDI ARABIA

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Abstract

Background: Down Syndrome (DS) is a genetic disorder that causes various intellectual and physical developmental problems. Despite the high incidence of DS in Saudi Arabia (SA), there is a dearth of research on the experience of families—especially of the primary caregiver (mother)—with a child with DS in SA. Additionally, the effect on a caregiver's life of caring for a child with DS in SA is not clear.

Objectives: To present the findings of interpretive research which identified and described the qualitatively different ways Saudi Arabian (SA) women as primary caregivers' understood the experience of caring for a child with Down syndrome (DS).

Methods: We conduct a qualitative study as an innovative research design during November 2011 to January 2012 on 18 mothers caring for children with DS in Riyadh, Jeddah and Dammam in SA. Methods were guided by accepted phenomenographic approaches to data collection and analysis. Semi-structured interviews were undertaken with 18 Saudi mothers caring for children with DS from centers in three regions of SA (Jeddah, Riyadh and Dammam).

Results: Five categories of description were identified and revealed unique awareness of the group and provide insight into their personal, social and collective understanding (being excluded, being isolated, being disappointed, having difficulty accessing services and needing support). The findings contribute to knowledge needed to support mothers caring for children with DS in SA. The research is useful to inform strategies for supporting families of children with DS, women in similar contexts, and healthcare disability policy and implementation.

Conclusions: Mothers caring for children with DS in SA have qualitatively different understanding of their experiences in caring for their children with DS. In this article Implication are discussed

Disclosure:

I certify that this paper does not incorporate without acknowledgement any material previously submitted in any Journals; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the

Keywords: Down syndrome; Saudi Arabia; women; family; middle eastern culture; disability; carers; phenomenography; qualitative research

INTRODUCTION

Background:

Downs Syndrome (DS) is a chromosomal disorder resulting in an additional full or partial

copy of chromosome 21. This results in varying levels of impairment, from mild to moderate physical and cognitive developmental disabilities [1] and specific physical characteristics and health

problems [2]. Parents and siblings of children with DS in many countries report that their lives have been deeply influenced by experience of living with a child with DS [3, 4].

Quantitative research has examined the experiences and difficulties faced by families with a developmentally challenged child [5, 6, 7]. However, despite the specific nature of challenges, many have adopted qualitative approaches since the late 1980's, when researchers began exploring how parents interpret their situations when raising a child with a disability including child with DS [8, 9, 10, 11, 12, 13]. Predictably, recent research has found that every family reacts and behaves differently when raising a child with DS; that there is no universal definition of their experiences and that it is an individual, unique experience that is embedded in a cultural and social context [14].

The quality of life of families caring for children with DS is unknown in Saudi Arabia (SA), but it is known that most primary caregivers tend to be women (mothers) and caring practices and experiences are bound deeply within well-established social and cultural traditions [15]. There have been significant changes in all areas of life for women in SA, particularly in relation to gaining permission to undertake paid work, the minimum age for marriage and the availability of education [16] significant restrictions on women's lives however do remain. Saudi patriarchal traditions remain and demand that women follow the instructions of men, and that only men speak on behalf of the family [17]. Women must get permission from their legal gaurdians (which may be their father, husband or son) before they can work, travel, study, marry or access medical care [18]. Women are respected as an important part of the family in Saudi society, but there are restrictions to their behavior, actions and rights.

Objectives:

It is essential to understand the specific needs of this culturally specific group through comprehensive and systematic research. It is important that specific experiences faced by Middle

Eastern women caring for children with DS (including those in Saudi families) be identified, in order to inform planning for the needs of mothers of children with DS, and to put in place recommendations for strategies that assist them in caring for children with DS. This study will map the qualitatively different experiences of mothers caring for a child with DS within the broader context of the meaning of disability and normalcy in the society of SA

MATERIALS AND METHODS

Study Design:

We conducted a phenomenography study during the period of November 2011 to January 2012 on collecting data from 18 mothers with experience of caring for a child with DS in three region of SA (Jeddah, Riyadh and Dammam), for regional and cultural reasons, and due to the travel distance required of the researcher. Research was completed at the 18th interview but saturation of the information was provided.

Collection of data took the form of a semi-structured interview. Non-technical questions (open-ended questions) constituted the interview and arose from the mother's experiences in caring for their child with DS. The interview questions are designed around 'what' and 'how', in order to extract variation [19]. Each interview took approximately 45–60 minutes. All interviews were conducted in the Arabic language, audio-recorded by digital tape recorder and reviewed for the quality of recording on the same day. Data was first transcribed verbatim from the audiotapes, in the participant's native language (Arabic) for analysis, and relevant data arising from the analysis and findings were presented in both Arabic and English.

Data analysis was undertaken in Arabic. Analysis involved seven phases [20] including familiarization, condensation, comparison, and grouping, articulation, labelling and contrasting. The whole process involved continual selection and

comparison of meanings arising from transcripts [21, 22] and concluded with the identification of a structural relationship between conceptions, including the construction of a diagrammatic representation in the form of an outcome space.

Ethics approval was granted by the Ethics Committee of the Queensland University of Technology (QUT). Ethics approval in SA was also obtained from the Help Centre in Jeddah, the Down Syndrome Charitable Association in Riyadh and the three centers in Dammam (Rehabilitation Society for Disabled Persons, Al Tahadi Centre and Al Wahaj Centre of Day Care). The researcher ensured that participants' physical and psychological well-being was protected. Written informed consent was obtained from all mothers. The participation of mothers of children with DS is voluntary and the data collected during the study has been handled confidentially. The level of risk to the participants was perceived to be minimal, but there was always the possibility that minor (emotional) discomfort would occur, due to sensitive issues or unpleasant experiences.

Measures: The researcher monitored continuously and sensitively for unexpected events, and was always prepared to give the participants the option to continue or end the interview. Further, the researcher obtained confirmation from the centers that a referral for counselling with qualified professionals (psychologist/social worker) within the center would be provided if the participant's discomfort persisted.

Inclusion criteria

Mothers having a child with DS (girl or boy) between the ages of five and nineteen years; the primary place of residence being in SA; of Middle Eastern descent; able to speak Arabic; no restrictions on education/qualifications; aged 18 years or above and from any socio-economic background; and being a married or single mother.

Exclusion criteria

Mothers being of non-Saudi descent (because this research concentrated on Saudi mothers only); fathers (due to cultural restraints it was too difficult for the researcher to interview males); and people who were not willing to sign the consent form.

RESULT AND DISCUSSION

Results:

Five conceptions as holistic and a collective understanding of the qualitatively different ways mother's experience caring for children with DS identified

Conception 1: Caring for children with DS as 'being excluded'

Living the experience of exclusion was an integral part of the whole experience of having a child with DS, because living with exclusion was a part of all of their lives. As women, it was part of their lives before having a child with DS, and was accentuated further after having a child with DS. Exclusion is their cultural norm and the following mother, when asked how she felt, stated:

We were always excluded from everything since we were born, so why should I bother if no one includes me with information about my son?

The exclusion of women from decision making is part of their lives, and women sometimes perceived themselves unable to take responsibility or make decisions on their own. They believed that men (the husband) owned the right to take responsibility for decisions relating to their life and children. Women's experience related to working at home and having minimal influence in decisions about pregnancy or a child's condition, future and education. For example, the following mother said:

My husband was refusing at the beginning to take him to the center to learn because at the end it is his decision to decide and I cannot disobey him. I had reached the point where I could not sleep at night thinking of how to convince my husband to agree.

Then he agreed. It took me three years. I brought him to center at age of four or five.

Conception 2: Caring for children with DS as 'being isolated'

All mothers stopped socializing when they discovered that they had a child with DS. Often they feared that their child would not be accepted in public or by people close to them. For some mothers, these fears proved correct, as they experienced social stigma for example in shopping malls or hospital. This mother explained:

We suffered from the people when they look at her, and you hear words that bother you like oh God, poor child, God help her. Once I was in a mall with her and one of the mothers withdrew her child away from mine telling him no, no, she is crazy get away from her. Of course what do you expect me to feel? It was sadness, angry and crushed, so I became isolated with her at home.

Isolation and the behavior of children

In SA, the only place that mothers can socialize and meet people is through family gatherings. The presence of a child with DS who is difficult to control requires justification. At weekends, women visit their family with their children, and there can be 20 people in one place, including sisters and nephews. Such gatherings are important for families to bond and build relationships. It is a time that mothers enjoy but for mothers with a child with DS, behavior of the child can often lead to withdrawal from these gathering. The following mother explained:

... my sisters have developed fear whenever we meet for their children and that makes them sit tense. So I stopped going to them because I get fed up every time we meet, I have to take care so he does not hurt their children and I become tense.

Isolation and caregiving

Lack of understanding combined with SA culture for women meant staying at home for long periods to care for their disabled child was common. Mothers described isolation leading to stress, anger and depression. Although many mothers did receive considerable support from

family members, participants explained that caring for a child with DS required much effort and many hours of constant care as the following mother explained:

we find that parents are forced to stay at home for longer periods, which leads to isolation and therefore they feel lonely.

Conception 3: Caring for children with DS as 'being disappointed'

Discrepancy between their child and prior dreams of a perfect baby caused profoundly negative experiences. Mothers experienced disappointment when their child did not coordinate with their hopes and expectations. They described a process of grieving from birth, which extended after their discharge from hospital. Mothers explained that the process was later replaced by updating, rebuilding and giving up some of their hopes and expectations prior to their child's birth. The realities of their child's actual prognosis and capability combined with a need to accept the situation. The following mother explained:

I have been through a difficult time of sadness and disappointment It took me a long time to give up my dreams and my plans for his future when I was pregnant and to accept him.

Mothers expressed disappointment through a range of emotions. They described a period of denial because they were strongly attached to their hopes and dreams about their newborn. For example, one mother said:

I refused to listen to the doctor when he came to tell me, and I told him I do not want to know anything, I am happy with my son and that's enough, I refused to believe that he is Down.

Conception 4: Caring for children with DS as 'having difficulty accessing services'

Exclusion from equitable access to healthcare and social and rehabilitation services was described and access to services was not provided equally between males, females and the disabled. In SA, women's access to services is never equal

to that of men. Mothers experienced societal barriers that prevented their child from accessing basic social and health services to develop to their fullest potential such as, cultural influence, healthcare worker attitude and lack of early intervention centers. Mothers experienced difficulty accessing healthcare services because guardians were too busy to take them, or believed that the child did not need medical care. Guardians used their position as a political tool, especially if they believed a child to be worthless or not warranting care at a hospital or education center they would make it difficult for the mother to access needed services. The following mother said:

His father always prevents us from taking him to the hospital when he has a chest attack. I hardly get an early appointment for him but what can I do? I cannot take him without his father's permission.

Conception 5: Caring for children with DS as 'needing support'

Mothers in this study believed that support, both within the family and society, was not just about people being with them, but included psychological, social, medical and physical support. Social support and personal coping resources were crucial for the families of children with DS. There was much stress in their lives and mothers described being overwhelmed by caring for their child on top of their other household responsibilities. The following mother said:

It is too hard to take care of a Down syndrome child. He needs a lot of effort and time.

Mothers looked to informal support networks for assistance and guidance, such as relatives, friends and neighbors. Among informal networks, the extended family was the main source of support for coping with daily life demands. Support of grandparents was essential. According to the culture and traditions in SA, mothers largely get support and assistance from grandparents, older siblings, aunts and elder cousins. The following mother stated that:

At the night of delivery I called my mum and told her that they doubt that she might be like my cousin

with DS. So she told me so what if she is DS, the one who gives you this child is going to help you. I could not forget these words from my mum; it was like cold water which released me psychologically. Thank God that my parents supported me otherwise I would have collapsed.

Lack of empathy

Mothers described a culture of rudeness and illiteracy in the broader society which shapes cultural expectations and norms. If a child is perceived to be normal, he/she will be accepted and expected to have advantages. But if the child is not perceived normal, such as if they have a disability, they are often rejected socially and experience rudeness. The following mother explained:

People do not appreciate, to them, since they knew that he is not normal, they reject him without putting themselves in the mother's place or what are her feelings and what she is going through.

Lack of information

Carers described a lack of adequate information about their child's condition, poor availability of disability services, and limited training on how to care for a disabled child. They believed knowledge about DS and their child's potential reduces ambiguity regarding their situation and future. Ignorance was a constant battle for mothers:

When I heard about the diagnosis and getting sure that he is Down, I wanted anyone to explain to me what does this mean, why down, and how can I treat him, as I know nothing. Doctors never gave you any information as a pediatrician. The books did not help me, it just showed genetic issues but did not tell me what is his future, what will happen to him, how to treat him. I do not know these things. The lack of knowledge affected me psychologically to the extent that I am not able to take care of him.

They believed that knowing and understanding were the greatest motivators for mothers as they prepared to care for their child.

Supporting understanding through DS centers.

Joining a public or private DS center was supportive and helpful in understanding and gaining knowledge and encouraged ways of better caring

for children. Through attending a center mothers were assisted to achieve the best possible outcome for their child. Staff explained about DS, provided strategies how to deal with children, and addressed questions and concerns about each child's condition or behavior. The following mother explained that she gained a lot from a center:

Before she was entered to the center I was a shamed of her or to go out with her, and this isolated me from meeting people. But after she started in the center and I understood her situation and how to deal with her I stopped being ashamed of her and take her out in every place and I was proud of her progression.

Mothers described achieving greater self-confidence and feeling better about themselves. Many no longer felt excluded and worthless with their role of caring for their child. Centers provided them an opportunity to feel empowered and strong. They described feeling proud of themselves and their achievements in caring for their children. Mothers felt that they were achieving something that belonged to them through their efforts and was especially so when people asked them how their child was progressing, as the following mothers noted:

I feel proud when someone asks me about my daughter and how they could talk and understand. I feel that I did something big and I have a goal that I have to achieve and that people start to give attention to my effort.

Mothers' support groups

Mothers found groups to be empowering as they often found ways of reacting and dealing with difficult behaviors such as stubbornness or over-activity. Their experiences resulted in changed behaviors:

Now he started to be stubborn as he used to wake up easily now he resists waking up just because he knows that it bothers me. There are outstanding mothers talking about stubbornness and how to deal with it. At the beginning I was fighting with him when waking him up in the morning and I hit him more than once as I wanted him to wake up early. I

started to learn from them, and then I stopped hitting him.

Outcome space

In accordance with the creation of pictures as a method of explaining experience and understanding of the different way mothers experiences caring for their child with DS. The outcome space (Fig. 1) is portrayed as cup. The outcome space illustrates the internal horizon (how component parts of the phenomenon are understood and are related to each other) of experience and understanding and the external horizon (the way in which the phenomenon is related to its context). The internal horizon presented in (Fig. 1) refers to how component parts are related logically. The phenomenon as a whole is represented at two structural levels. Level one is the conception of being excluded, which is highlighted as a pervasive experience that affects all other awareness and positioned purposefully at the center of the diagram, so as to highlight the way that it sits central to all experiences associated with the phenomenon of investigation.

The second structural level includes all four boxes (the four remaining conceptions) floating in the cup, and within the fundamental experience of being excluded. They each represent distinct parts of a whole understanding of the phenomenon. Each box floats in the cup, but they have no hierarchical or linear structure, as they are all experiences at level two, and occur without a linear occurrence. Each conception has its own integrity and form and still remains a conception, yet they float in the experience of being excluded. The conceptions are distinct, independent experiences that highlight the possibility of awareness. They are each part of the whole that each mother may or may not experience.

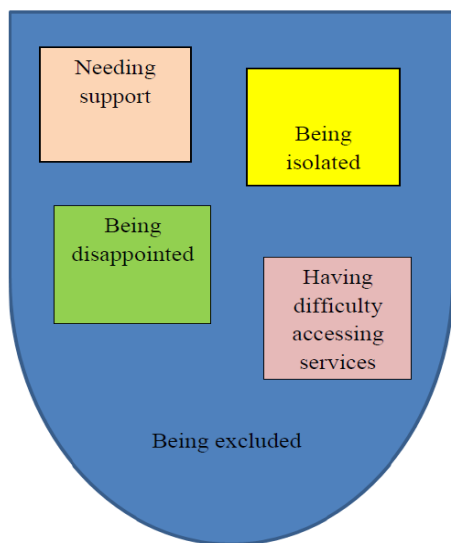


Figure 1: The qualitatively different ways mothers

experience caring for children with DS in SA

Referential aspect

In this research, the phenomenon of understanding is dominated by the desire of mothers to gain acceptance. Desire for acceptance is an explanation that draws all five experiences together and highlights an increasing level of awareness by mothers as they learn about life with a child with DS. Mothers referred to their desire to be accepted

at all levels of society, and to be acknowledged and supported in their attempts to do their best to care for their child with DS.

External horizon

In this particular study, experiences at the external horizon were related to marginalization and the ways in which women are treated within Saudi society. This marginalization defined and framed the way that the particular phenomenon emerged as part of their experience. Marginalization positioned at the margin of the external horizon assists in defining the margin of the internal horizon, and the way that each of the five conceptions emerge for women in their internal awareness of the phenomenon. Thus, in terms of the layers of awareness, marginalization was the outer layer and experiences of caring for a child with DS at levels 1 and 2 [Table]. In other words, although caring for a child with DS was experienced in qualitatively different ways at levels 1 and 2, it was always experienced within the frame of marginalization.

Desire for Acceptance	<ul style="list-style-type: none"> - Needing support - Being isolated - Being disappointed - Having difficulty accessing services 	Level 2
	<ul style="list-style-type: none"> - Being excluded 	Level 1

Table 1: Caring for a child with DS in SA

DISCUSSION

This research describes the qualitatively different ways a group of women understood the phenomenon of caring for a child with DS in SA. Awareness highlights needed challenges in SA and the need to improve the lives of carers and children with DS. Caring has a direct effect on women and significant improvement is needed to the quality of childcare provision for disabled people in SA society. Participants described experiences that partially resemble experiences of carers in modern societies but other aspects resemble little of what is recommended in Western-based literature. SA needs implementation of adequate services and programs for families and their children, and significant changes to the social and cultural lives of women.

The findings support literature on the importance of emotional and instrumental support, the potential for positive religious and traditional family values, and the need to develop independence for women because it directly impacts on the care of a child with DS as a family member and a member of society [8, 23, 24]. There is a growing body of research that confirms the importance of positive support in assisting families, where the goal is to increase families' quality of life and foster the positive growth of the child with DS [25, 11].

Evidence affirms the effectiveness of women's support groups for various health problems (such as postnatal depression, breast feeding or breast cancer) because they facilitate trust, which opens a portal for sharing information, learning new skills, talking about thoughts, fears and feelings, and engenders connections [26]. This study's findings emphasized the positive role of mothers' groups not only within centers, but also those organized by mothers themselves through social media.

Failure to implement government legislation, low education levels for women, socially repressive cultural values, and stigma related to disability are primary causes of the isolation of mothers in SA. The combination of paternalistic cultural traditions, intolerance, ignorance and exclusion is a disappointing social phenomenon in SA that is expressed overtly towards carers and the child with DS. Given awareness of social isolation and sorts of exclusion described by participants, and the lack of similarity between current Saudi programs and evidence-based programs elsewhere, there is enough evidence to conclude that the government and the people need to do more for the families of children with DS.

The situation for persons with disability in SA is mostly viewed from a medical and charity perspective, within a backdrop of limited and often outdated legislative and policy frameworks that claim to adhere to WHO guidelines. The inadequate situation effects mothers of children with DS, and is exacerbated by cultural, traditional and religious factors that have resulted in significant difficulties in accessing disability services, inadequate progress towards inclusion and a failure to remove substantial barriers to the participation of persons with disabilities in society.

Limitation of the study

While the researcher attempted to take a second-order perspective—that is, to view the phenomenon from the perspective of participants—it was not possible for the researcher to be that person [27, 28]. As such, the results of this phenomenographic study include the researcher's interpretations of the communication with the participants. As the researcher was a registered nurse and a clinical nurse in a pediatric ward, and the daughter of a mother who cared for a child with DS, she had personal and professional views and experiences relating to the research topic. The researcher

implemented a range of strategies throughout the research process that were all successful in supporting the trustworthiness, credibility and rigor of the research outcomes.

Conclusion and Recommendations

Attitudes towards people with disabilities and their families must change, as should legislation. This provides evidence to inform debate and consideration of daily experiences of Saudi women, and contributes evidence for the ongoing development of strategies aimed at improving knowledge and practices regarding support for them. The research should be used to inform the improvement of services and education strategies provided to women caring for children with DS in SA. Replication of this study is recommended to identify any additional conceptions, and qualitative research studies should be more broadly undertaken to explore caregiving in SA. Additional future research is also suggested, with a focus on establishing reliable population data and the design of interventions that would specifically assist Saudi women make equal contributions to the country, based on inclusion and acceptance.

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