

# Caregivers' perceptions and experience of caring for persons with Down syndrome in Kuwait: a qualitative study

Amna AlShatti, Dana AlKandari, Hessa AlMutairi, Dalal AlEbrahim, Abdullah AlMutairi, Danah AlAnsari, Lulwa Abduljaleel, Hassna AlEnzi, Latifa AlFoudari, Hamad AlShaib, Khalid AlAzmi and Jamil Ahmed 

Department of Family and Community Medicine, College of Medicine and Medical Sciences, Arabian Gulf University, Manama, Bahrain

**Aim and Objective:** This study aimed to explore how caregivers of persons with Down syndrome (DS) believe caring had an impact on their own lives. A secondary objective was to understand their experience of seeking educational, social, and health care services for the persons with DS.

**Methods:** This qualitative exploratory study was conducted with 21 caregivers of persons with DS in Kuwait.

**Results:** Caregivers struggled to accept the diagnosis initially that led them to search for answers to many of their concerns about raising a person with DS. For the caregivers, who mostly comprised of mothers, dealing with health conditions that persons with DS suffered from was initially difficult. Caring for these individuals led to heavy impact upon their caregivers' own lives who took extraordinary efforts to cope with the burden. Seeking quality education for the persons with DS and participation in social activities was also challenging, and the caregivers believed that better services, facilities, and benefits for the families of persons with DS may help them better cope with the socioeconomic and psychological burden.

**Conclusions:** Improving the availability of specialized services, the delivery of guidance and counselling, and social integration may help overcome challenges of raising a person with Down Syndrome.

**Keywords:** individuals with Down syndrome, caregivers' perceptions, experience, Kuwait, qualitative study

## Background

The estimated incidence of Down syndrome (DS) is between 1 to 10 per 1000 live births worldwide (World Health Organization 2020). As stated by Catalogue for Transmission Genetics in Arabs Database, which covers the period from the late 20th century to the early 21st century, the incidence of DS in the Arab world is higher than internationally (Centre for Arab Genomic Studies 2013). In the Gulf region, United Arab Emirates has an incidence of DS of 1:449 (Corder *et al.* 2017), while Oman 1:500, Qatar 1:546, and Saudi Arabia has an incidence of 1:554. The incidence of DS in Kuwait is estimated to be approximately 1:581 (Centre for Arab Genomic Studies 2013).

Persons with DS are highly susceptible to complications like hearing and vision loss, heart defects, obstructive sleep apnea, hematological disorders, and dementia, increasing their need for highly specialized

healthcare services (Kazemi *et al.* 2016, Santoro *et al.* 2020). Persons with DS experience delayed development of motor functions as they take longer than their normal counterparts to achieve developmental milestones, such as crawling, walking and speaking (Malak *et al.* 2015). They are known to suffer from varying degrees of neurobehavioral disorders, with majority facing difficulty in learning, language, and memory (Capone *et al.* 2006). Significant reduction in independence and communication skills, and progressive cognitive deterioration is observed in more than a quarter of DS individuals aged over 30 and in most after the age of 60 years, leading to prolonged burden on their caregivers and the healthcare services (Grieco *et al.* 2015)

Persons with DS also experience several societal challenges. A lack of suitable employment opportunity is likely to affect young persons with DS who are reported to experience greater difficulty in accomplishing their social roles including but not limited to maintaining relationships, leading a community life, participation in sports and recreation, and fulfilling

Correspondence to: Jamil Ahmed, Department of Family and Community Medicine, College of Medicine and Medical Sciences, Arabian Gulf University, Manama, Bahrain. Email: jamilmga@agu.edu.bh

workplace responsibilities (Huiracocha *et al.* 2017). Maintaining hygiene and care could be challenging and communicating is particularly difficult for them because they behave and respond differently to social interactions, which others may perceive as abnormal responses (Malak *et al.* 2015). Housing is a major issue as many persons with DS require constant observation for their safety, causing which in some situations has led to parents demanding support from the governments to meet the growing needs of these children (Hsiao 2014). All these factors are known to lead to a higher dependence on their caregivers.

Caring for persons with DS is known to affect their caregivers in several ways. These caregivers may include their mothers, fathers, siblings, housemaids, and other persons in care organizations. Most caregivers are known to live under psychological stress increasing their risk to poor mental health outcomes including depression (Mbugua *et al.* 2011). This is in addition to socioeconomic burden on the lives of these caregivers. This is because caring for a person with DS is a responsibility for their caregivers especially health-wise because of the presence of highly demanding medical and neurologic deterioration (Barros *et al.* 2017). As the persons with DS have reduced independence in performing daily activities, they require a high level of assistance from their caregivers, social and health services, and the community. (Marshall *et al.* 2015). Nevertheless, the parents have also been shown to experience positive impacts from having a child with DS (Bertrand 2019). This study aimed to explore challenges affecting persons with DS and their caregivers in Kuwait as perceived by the caregivers themselves. Specific objectives included to explore how caregivers of individuals with DS believe their condition affects them socially, psychologically, and physically in Kuwait, and to understand persons with DS the experience of caregivers in achieving education, and socialization for the persons with DS. A secondary objective was to understand the perceptions of caregivers about the facilities in Kuwait (financial support, healthcare services and rehabilitation) for persons with DS.

## Methods

### Study design

We used a qualitative exploratory study design, which was most suitable to achieve the objectives of this study to understand caregivers' experiences of caring for persons with DS. The qualitative study design also helped us understand perceptions of caregivers about the challenges that these individuals may have experienced while seeking educational, healthcare, and other services in Kuwait.

### Setting

Kuwait had a population of 4,464,521 by January 2020, of which 1,365,171 were Kuwaiti citizens and rest non-Kuwaitis (Central Statistics Bureau 2020). The Kuwait Medical Genetic Centre, established in February 1979, offers genetic services in Kuwait. With fully equipped laboratories for necessary investigations for persons with DS, in addition to providing antenatal and premarital counselling to parents. According to the premarital law No. 31/2008 premarital screening is mandatory to prevent genetic diseases in Kuwait. Kuwait also has three educational facilities dedicated to the persons with DS. These facilities include Kuwait Down Syndrome society, and two schools. The government of Kuwait and the Public Authority for the Disabled provides different services to the persons with DS according to their level of disability. Free of cost education is available for all members of the Kuwait Down Syndrome Society. Persons with DS and other intellectual disabilities receive a monthly stipend, driver and helper allowance, and a housing allowance to help share the socioeconomic burden on the families. Families of the DS individuals also receive free of cost hearing aids, wheelchairs, or visual support devices (AlShati 2019).

### Study participants and sample

Caregivers in our study included the legal guardians whether they were the parents, siblings, or close relatives of the person with DS, therefore they did not include housemaids. In Kuwait, the primary caregivers are mainly the mothers of persons with DS. Primary caregivers are the most insightful to phenomenon under investigation and what can be done for, and how to improve the lives of the persons with DS. These caregivers were selected from diverse age groups, educational background and geographical locations within Kuwait which allowed us maximum variation in our sample and helped capture a wide range of perspectives.

### Data collection

Data were collected during July and August 2019 by using semi-structured interview guide which was developed after review of literature. To recruit participants, we contacted Kuwait Down syndrome Society, "Naser Abdulrahman AlMejel Centre for Children with Down Syndrome", "Abeer Two and AlKharafi Activity center for kids with special needs". After arranging a visit to Al Kharafi Activity Centre for Kids with special needs, we found that it was closed due to summer holidays when we planned to collect data. A third center we contacted provided contact information of six caregivers, but we could not find them, therefore we continued to contact further participants through the lists provided by the first two centers until reasonable number of

**Table 1. Socio-demographic characteristics of the caregivers and the Downs syndrome individuals.**

	Caregiver's age	Relationship	Down Syndrome Individual's initials	Down Syndrome Individual's age	Age of mother when child was born
Interview 1 (17/6/2019)	37	Mother	A.A (middle child – 2 <sup>nd</sup> )	5	31
Interview 2 (18/6/2019)	39	Mother	B (last child)	19	
Interview 3 (18/6/2019)	55	Mother	N.A (last child)	18	38
Interview 4 (18/6/2019)		Mother	H (5 <sup>th</sup> - last child)	8	40
Interview 5 (19/6/2019)		Sister	S	30	>40
Interview 6 (19/6/2019)	28	Mother	H (3 <sup>rd</sup> child)	5	23
Interview 7 (20/6/2019)	29	Mother	F.A (Has a twin)	25	End of 30s
Interview 8 (22/6/2019)		Sister	A (9 <sup>th</sup> child) (comparing to others he was normal but overweight)	31	>40
Interview 9 (17/6/2019)		Mother	F (only child)	9	40
Interview 10 (18/6/2019)		Mother	A (5 <sup>th</sup> - last child)	23	41
Interview 11 (23/6/2019)		Mother	H (2 <sup>nd</sup> or middle Child)	7	23
Interview 12 (26/6/2019)		Mother	A (4 <sup>th</sup> )	39	30
Interview 13 (8/7/2019)	35	Mother	A (first child – 1 <sup>st</sup> )	6.5	28
Interview 14 (14/7/2019)		Mother	A (2 <sup>nd</sup> child)	14	36
Interview 15 (14/7/2019)		Mother	B (4 <sup>th</sup> child)	18	34
Interview 16		Mother	M (2 <sup>nd</sup> child)	23	35
Interview 17 (29/7/2019)	34	Mother	Z (1 <sup>st</sup> child)	10	21
Interview 18 (29/7/2019)	57	Mother	S (1 <sup>st</sup> child)	32	22
Interview 19 (3/8/2019)	55	Mother	M (4 <sup>th</sup> child)	22	40
Interview 20		Mother	M (last child)	5	41
Interview 21		Mother	A (last child)	7	40

caregivers were not finalized for the interviews. About 10 caregivers refused to participate in the research since they were hesitant to join the study. After contacting the participants, the location and timing of the interviews was set according to the comfort of the participants. Interviews were performed in the Naser AlMejel center, Kuwait Down syndrome Society premises, participants' offices, or their homes. The total of 21 interviews were conducted, with about six interviews a week, by three groups of year four Arabic speaking Kuwaiti undergraduate medical students. Each group comprised of two students and in each group, one person asked the questions while the other noted down any observations during the interviews. The senior author, a qualitative research expert, trained these six female researchers on the data collection procedures in qualitative studies. Initially, we interviewed 15 participants within a three-week period and stopped collecting further data as we believed that we had reached data saturation. After analysis of these interviews and seeking guidance from senior author, we believed that

continuing interviews may lead to new data. Therefore, we continued our search for participants and conducted six more interviews. Interviews were stopped when the co-investigators agreed that any subsequent interviews may not generate new data relevant to our research objectives. Interviews were performed in Arabic, and audio-recorded, and the duration of the interviews varied between 17 min to an hour and a half.

### Data analysis

The data were analyzed by thematic analysis (Braun and Clarke 2006), where interview data were coded, the codes logically merged, and themes identified and reported. During June 2019, several group meetings were held in which a plan was made, and data analysis strategy was agreed upon between the researchers, making sure everyone understood their role. The audio-recorded interviews were first transcribed verbatim into Arabic by a group of three researchers. Interview files were uploaded to Atlas.ti. The Arabic transcripts were analyzed and line by line coding was performed by a

group of three researchers. The coding process consisted of both, inductive and deductive coding. Codes were agreed upon between four researchers who analyzed the data systematically, identifying patterns in data to generate themes. Finally, the senior author validated the coding process and analysis by checking if the code names were correctly assigned, appropriate lines of the text were coded; and an agreement was finally reached to organize the codes into themes. The theme names were refined to answer a construct based on our objectives. Final themes were revised after thorough discussion between the researchers and the senior author, where we went back and forth to our data to confirm the themes. The language and dialect used by the participants was given due consideration; and for some of the local words that participants used were difficult to be translated to English and care was observed so that the actual meaning was not lost. The final summary of the themes with representative quotes were translated from Arabic to English by the researchers who checked the authenticity of the translation with other co-authors, and senior author.

### **Ethical considerations**

The study was approved by the Research and Ethics Committee of Arabian Gulf University, Bahrain (E021-PI-4/19) and the Ministry of Health, Kuwait (3058). A prior written and verbal consent was obtained from the participants. Participants were informed about the purpose of the study and they clearly understood that their participation in the study was voluntary. Initially, some mothers were hesitant about audio recording the interviews, and were hesitant about disclosing the information related to the questions by sharing their experience. However, the interviewers reassured them that the audio-recordings will be destroyed once the study is completed, and their identity will be anonymized, which encouraged them to speak openly in response to questions and probes. The recordings and information that could identify the participant was protected and secured through referring to each participant with an initial. After transcription was performed, all the interview recordings were deleted.

### **Findings**

We interviewed 21 caregivers whose age ranged between 28 and 57 years. Most were teachers, administrative assistants, security officers, bankers, housewives, or retired mothers. The persons with DS were aged from 5 to 32 years. Mothers were aged as young as 21 years, and as old as 41 years when they had their child born with DS. Eight of the 21 participants were at least 40 years of age when they had their child born with DS. Fourteen mothers had five children or less including their child with DS, and seven had at least five children, and only one person was the only child of

their parents (Table 1). Four key themes emerged from our analysis: caregivers' struggle after the diagnosis of DS, impact on the caregiver is huge, educational, and social participation by persons with DS is challenging, and perceptions of and satisfaction with inadequate services and facilities (Figure 1). The findings are presented based on the consolidated criteria for reporting qualitative research (Tong et al. 2007).

### **Caregivers struggled after the diagnosis of DS**

Many of the caregivers discussed several problems that included delay in the diagnosis, initial health problems these individuals suffered from, and a lack of awareness about the condition.

*"The physicians were in doubt because of her features were not clear yet (at birth) and the results (diagnosis) were delayed for 12 months" (mother of a 39-year-old female)*

In addition, they talked about difficulties they faced to deal with the new reality that they faced as they took time to understand the needs of their children. Shock was the most profound initial reaction. Most of the caregivers reported that, initially, nobody helped them to learn how to deal with their children's condition and there were limited options available to them to guide them about it. The main sources of information about the condition after the diagnosis were the health professionals; however, women lacked knowledge and awareness of DS at the time of diagnosis. They learnt to solve the children's problems by themselves, and some of them were lucky enough to find groups of caregivers who shared their own experience with them. The caregivers found this connection with other similar families extremely helpful.

*"I think in Kuwait they need to do more to care about this aspect (of diagnosis of a DS in a family). However, there is self-help group of people which creates awareness about children with special needs. The group has set up children's groups, arranges activities, campaigns and social networking events, but this is not a formal group." (mother of a 6-year-old male)*

Almost all caregivers struggled with dealing with the initial health problems that the persons with DS developed. These included congenital anomalies of the heart, hypothyroidism, obesity, low muscle tone, delayed walking and other milestones, cataracts, hearing, and speech problems. Caregivers discussed that the condition of their children was too hard to handle initially.

*"It is not easy to see your child suffering with the disease and (who goes through a major) surgery; and suddenly he is beside you and you are required to stay with him, take care of him and give him medicine" (mother of a 6-year-old male)*

Considering the challenges and complexity of the diagnosis, caregivers were often found to have made several personal efforts to improve the quality of their children's lives. Many caregivers had even stayed abroad for an extended period for specialized medical care for their children's conditions.

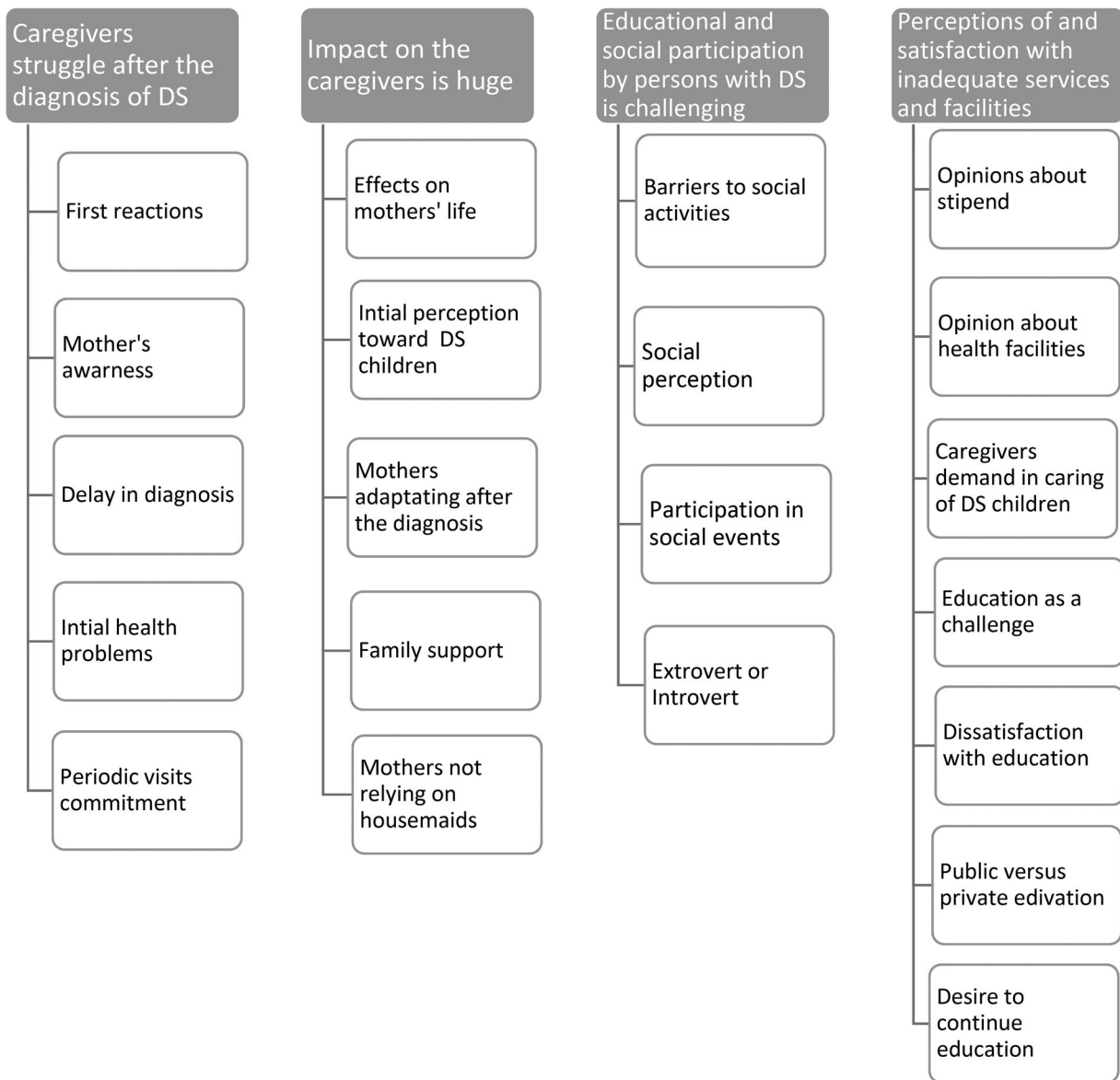


Figure 1. Four main themes, and the related nodes used to code the text.

*“He had an operation at the age of 8 months, and after that when he was one, we went for another surgery in the USA. And we lived there for a year for therapy and check-ups” (mother of a 6-year-old male)*

Some of them even had dedicated a room in their homes for physiotherapy. One of the caregivers negotiated with the doctors to start the physiotherapy earlier and insisted to know everything about the physiotherapy equipment, so she could buy and use it herself.

*“I tried with them and insisted until they accepted to do physiotherapy on her early, when she was very young.” (mother of a 19-year-old female)*

Majority of the mothers adapted to the situation and gradually started to accept their children’s condition after their initial stressful period. They perceived that having a child with DS was nothing less than a divine blessing. One mother said:

*“Allah loves me and (that is the reason He) blessed me with this child, and I used to tell my mother that this child is a gift from Allah” (mother of an 18-year-old male).*

Most of the caregivers reported that they were committed to the annual consultations without missing any of them. On the other hand, some caregivers were not committed, and believed that they could not commit to these consultations because of the long distances to the clinics or heavy city traffic.

*“Long distance to the health facilities and the heavy traffic were problematic (to go to clinics)” (mother of a 14-year-old female)*

Some of the caregivers went beyond that by admitting that they stopped taking the persons with DS for routine visits to the clinics because of their previous experience of medical errors by the healthcare workers. They believed that visiting these health providers could land their children into a new health problem.

### **Impact on the caregivers is huge**

The mothers in our study also did not seem to rely on their housemaids despite of a common culture of



employing housemaids in Kuwait. They emphasized that they were concerned and could not rely on housemaids to leave their children with DS alone with them.

Due to the special care that a person with DS requires from their mothers, most mothers had to quit their jobs, and several others had to take long leaves from work. According to the mothers, long working hours were a barrier for them to look after a person with DS. Some mothers said that because their husbands were also working, they decided that one of them should quit job to take care of the child.

*"In the beginning, I decided to stop working for a limited time and then thought of getting back to work. But I did not, because I figured out that she needs special care". (Mother of a 14-year-old female)*

Some mothers mentioned that having a person with DS affected their social lives to the extent that it was not easy for them to participate in a family event. Another reason for a toll on caregivers' social life was that they could hardly find time from a busy schedule comprising of hospital appointments, educational sessions, and physiotherapy.

*"I became isolated from the world while I took care of my child, I did not have enough time to recognize what had happened because we spent most of our time in the hospital". (Mother of an 18-year-old male)*

The persons with DS in our study also seemed to have impacted their mothers' daily activities. Few caregivers agreed their daily life was not much affected, while others said that they had problems with finding time to rest and perform chores like going out for grocery.

*"I wake up every two hours at night to check if he has any problem, because he does not cry for help". (Mother of an 18-year-old male)*

Caring for the persons with DS also affected the caregivers' mental wellbeing. Some women discussed that they experienced severe mental health problems which ranged from denial of their own children to depression, however our study did not explicitly assess depression in these caregivers.

*"It was so hard that I could not accept my own child, I mean I was in denial" (Mother of a 5-year-old male)*

In our study, participants mentioned a range of challenges that they experienced while taking routine care of a child with DS. Some talked about their experience of frustration when their children behaved aggressively with other children. While others said that other children also avoided playing with their children with DS because of their abnormal behavior or difficulty in communicating with others.

*"I suffer while waking her up for school because she is so persistent (and would not leave bed easily)". (Mother of a 22-year-old female)*

*"She is hyperactive and has a violent behavior. Sometimes she hits other children, which makes people get angry; and this irritates me internally because she does not understand". (Mother of a 7-year-old female)*

### **Educational and social participation by children with DS is challenging**

Most caregivers of DS individuals agreed that their children were able to socialize reasonably with other people. They emphasized the importance of the family's support which they believed also included the role of siblings in building the personality of a person with DS. Other caregivers spoke about the need for treating a person with DS equally in the family so that they may not perceive themselves special or different. Other caregivers said that their children had an introvert personality because of speech difficulties.

*"He gets very saddened when he talks with people who often do not understand him. This problem made him unsocial" (mother of a 23-year-old male)*

Another reason for barriers to persons with DS to participate in society, according to the caregivers, was the society's perception about these children. The mothers discussed that although social acceptance of the persons with DS has improved recently, there still existed some sensitivity. Some people over-sympathized with the persons with DS, which the mothers described as "discomforting". Most mothers did not like people being sympathetic towards their children all the time. While some people were still apprehensive towards persons with DS.

*"There are a lot of people who pretend to be kind, but they are not actually like that. Sometimes I take him to places and they ask me that why I had brought him there, they do not want him there." (Mother of an 18-year-old male)*

Caregivers responded that the persons with DS wished to participate in extracurricular activities if they had the opportunities. Several contests were mentioned by the mothers, like basketball, bowling, theater, and Quran memorization; in which many of these children have previously participated. In addition to these events, persons with DS have an interest fields like photography, carpentry, and handicraft. However, the caregivers believed that the persons with DS needed exceptional attention, which may not be available to everyone.

*"I have noticed that she loves sports, so I found her a private swim teacher. She learned to swim successfully but once the lessons stopped, she forgot everything. They are like that; they need consistent care." (Mother of a 14-year-old female)*

As the summer clubs focus on the entertainment rather than education, according to the caregivers, schools should provide required academic training. Although this was achieved in governmental schools, these schools only offered education up to the elementary level. In addition, some mothers noticed that their children had difficulty in adapting to the school environment and socializing with other students.

*"There are specific teachers for the children with special needs, but the school is not understanding, and they put the special child in a special needs class and put a specific time for recess and*

*food and activities for him. So, the mixing is merely just a word for the school" (mother of a 6-year-old male)*

Because of these limitations, some caregivers preferred private schools. However, they still faced challenges there as well because, as some participants were also concerned that, most private schools imparted only skill-based training for persons with special needs in Kuwait, and that the academic learning, which was missing in these schools, was equally important. Most participants were dissatisfied with the education their children received, and caregivers had a persistent desire to improve their children's learning abilities. They were willing to dedicate their lives for their children, because they said that they believed that the persons with DS could also have a better future. On the contrary, some caregivers also believed that education and employment were not that important for the persons with DS as they were for the normal children.

*"they always say that your son doesn't want to learn, or his reading ability is weak, and this is what being said for every mother. Tell me who is the excellent student that they thought? They are the beneficiaries, and our children are not." (mother of an 18-year-old male)*

### **Perceptions of and satisfaction with inadequate services and facilities**

The caregivers' opinions about their satisfaction with the quality of the care received for the persons with DS, varied according to their area of residence. Those who lived in areas near large tertiary care hospitals were more satisfied with the health care services compared to those who lived in remote areas. Many were satisfied with the pharmacy and laboratory investigations available under one roof, which they believed saved them precious time lost in making multiple visits to different specialized centers. Most were satisfied that they received priority while visiting these centers.

*"Yes, the hospital is indeed very good, and doctors are highly qualified and always give priority to my son" (mother of a 5-year-old male)*

Other caregivers were concerned with the scarcity of hospitals providing specialized care for persons with DS in their areas. They complained of the difficulty in accessing the healthcare facilities, delays in receiving laboratory tests results, and unavailability of radiological, genetic, nuclear medicine, and other interventional investigations at their local centers. Because of that, most of them said that they preferred to directly visit a tertiary care hospital which was often located far from their homes.

*"We live in A.M. area and there is no specialized center or tertiary care hospital in my area" (mother of a 23-year-old male)*

Most caregivers talked about the need for specialized dental clinic and physiotherapy center to treat the dental and other health problems of persons with DS. They

suggested to establish specialized health centers with adequate availability of skilled medical staff, nurses, physiotherapists, and nutritionists to take care of children living with DS in areas where these services are necessary. They also discussed the need for specialized gymnasiums for persons with DS which they believed would help address the problem of overweight and obesity in their children.

*"I went to a gym with my daughter and they said that they do not accept her kind." (Mother of a 32-year-old female)*

In response to our question about financial support by the government for their families, most agreed that the financial assistance provided by the government was enough for them to meet the needs of the persons with DS.

*"The government sends us money every month and it's enough for his needs at this age". (Mother of a 5-year-old male)*

### **Discussion**

This qualitative research explored the challenges faced by persons with DS and their caregivers in Kuwait. Our analysis highlights that caregivers of the persons with DS often struggled with adapting to the new realities of the caring for a person with DS, at least at the time of diagnosis. Despite of an initial period of shock and disbelief at the time of diagnosis, it took the caregivers some time to accept the fact that their children will live with long term mental and physical challenges and disabilities associated with DS requiring their care and support for the rest of their lives. Caring for children with DS had heavy toll on the lives of the caregivers themselves. Most had sacrificed their careers, dedicated their lives to perform highly challenging and full-time job of looking after their children. This also affected their own mental wellbeing, as many seemed to be frustrated, stressed, and tired of striving to meet the behavioral and educational needs of the persons with DS. Educational attainment, adapting the school environment, and participating within community, and socializing with other children was difficult for the persons with DS. Despite of these challenges, the caregivers were generally satisfied with the public services and incentives provided to them, except some who lived far from the tertiary care hospitals who believed that accessing specialized care, particularly dental care, physiotherapy, and advanced laboratory tests was challenging for them.

Consistent with a review which highlighted the occurrence of disappointment and surprise after diagnosis of DS (Schimmel et al. 2020, Smith et al. 2019), our study also showed that after the diagnosis, many of our caregivers expressed feelings of shock and denial, while others suffered from mental distress which could possibly be depression. However, with the passage of time, the caregivers accepted the reality and adapted to

the challenge of caring for the persons with DS. This was possibly because the caregivers of persons with intellectual disabilities often meet in social organizations where they discuss and share their experiences which may have improved their knowledge of what comprised of a better care. Our findings, that some caregivers finally reconciled with the challenge of raising a child with DS and that there were others who believed that they were blessed to have a special child, are consistent with a study from France where most parents were happy with a special child, to the extent that they said that these children had a positive impact on their lives (Bertrand 2019), or with a study from Denmark in which the parents described that these children were "given" to them (Lou et al. 2020). Informing parents about the diagnosis through a, supportive, empathizing and caring manner considering the specific cultural context may help reduce the impact of the breaking the news of the diagnosis of DS (Schimmel et al. 2020).

Caring for a person with DS is accompanied with a heavy burden of poor mental and social wellbeing (Barros et al. 2017). Findings from this study showed that some caregivers had sacrificed their jobs, daily activities, and social life to ensure a healthy life for their children. Studies have consistently showed a high level of stress among parents of children with intellectual disability disorders like DS, as well as autism (Gashmard et al. 2020). Depression in parents of children with DS has been shown to further aggravate learning and language abilities (D'Souza et al. 2020). Studies have shown that depression and stress in parents could be caused by poor acceptance of the diagnosis (Gashmard et al. 2020). Despite of the stress of performing highly demanding tasks associated with caring for a child with DS, the women in our study adopted several coping mechanisms including finding help from the support groups and sharing their worries with their peer. Studies have shown that using positive adaptive mechanisms such as emotion oriented coping can help reduce depression and stress among these parents (Gashmard et al. 2020).

This study showed two main factors which influenced a person with DS to socialize in Kuwaiti society. First is that parents need to treat and care for the persons with DS equally without any discrimination to create a sense of "normality", and second is the support and care by a sibling. Compared to this support within families, caregivers in our study believe that it was difficult to control the way people treat persons with DS. Generally, the Kuwaiti society increasingly accepted the persons with DS, however young people still had some sensitivity towards the former. Elsewhere, studies have shown how societies can be negative towards children with DS (Huiracocha et al. 2017).

Many participants in this study talked about how it was challenging for their children to socialize with other children. It was partly because of their aggressive behavior and a lack of ability to clearly communicate, and partly because of the way other children identified them. Studies have shown that such behavioral difficulties are associated with stress and other mental health difficulties among caregivers (Ashworth et al. 2019). In schools, the main barriers to socialize included a lack of participation in extracurricular activities. The caregivers believed that this was because the public schools run separate program for children with DS leading to poor mixing with the rest of the children. Raising awareness and communicating these concerns with decision makers in educational institutions may help improve educational quality and fulfill social needs of children with DS (Van Herwegen et al. 2018). Elsewhere, consistent with our findings, parents have voiced for a supportive, non-discriminatory, and non-judgmental environment for persons with DS to flourish and grow (Krueger et al. 2019, Lee et al. 2019, Liu et al. 2020).

Persons with DS require special and empathic care since they are predisposed to a wide range of diseases and complications. Our results are consistent with studies showing that the primary caregivers require support from health professionals in dealing with their children's medical conditions and risk factors (Borthwick et al. 2019, Hu 2020). Health professionals have a role in imparting positive information and support for the caregivers so that they can look forward to a positive future for their children with DS (Marshall et al. 2015). A qualitative study from Netherlands proposed a coordinated healthcare within the existing support networks, and a trust enabled patient centered approach to tackle healthcare barriers experienced by persons with DS (van den Driessen Mareeuw et al. 2020). When parents start their journey of providing care after the diagnosis, they often feel unprepared to raise a child with DS (Gashmard et al. 2020). Health professionals must provide adequate knowledge and awareness to the primary caregivers to prepare them to address and seek help for any new health problems in persons with DS. Educating and supporting caregivers by providing adequate opportunities of training about parenting techniques is associated with reduced stress (Phillips et al. 2017).

While most caregivers were satisfied with the financial assistance provided by the government, some were still not pleased with other facilities. The most serious problem which was encountered by our participants was the unavailability of specialized medical staff to deal with DS and its complications. Oral healthcare for the persons with DS was a major concern by the caregivers, which could have been because dental deformities are common in persons with DS and a high level



of independent oral care is not expected from persons with DS (Kalyoncu et al. 2018, Scalioni et al. 2018). Caregivers also emphasized the importance of providing resources such as dedicated gymnasiums to improve their physical activity and prevent obesity in persons with DS. Persons with DS are known to have low level of physical activity and higher risk of obesity (O' Shea et al. 2018). Parental involvement is key to improving the time spent on physical activity by the persons with DS (Alesi and Pepi 2017), and also the parents themselves (Diaz 2020). Some other participants highlighted the need for dedicated physiotherapy and speech centers in Kuwait, which are vital for these children as they take longer than normal children to achieve milestones.

### Strengths and limitations

Using a qualitative method had its strengths and limitations. Open ended questions gave our participants freedom to express their emotions without feeling limited, which was a strength of this study. This research comprised of interaction between local female interviewers in the Arabic language, which improved the communication and trust during the interviews. Another strength of the study was the stepwise data collection approach in which the preliminary data were processed to determine if the research would require further data collection. Guidance by an expert qualitative researcher helped adhere to the methodology, rigor, and criteria of qualitative research in this study. Our study also has some limitations. Interviews may be biased towards the opinion of mothers, since no fathers volunteered to participate in the research. About 10 caregivers refused to participate in the research since they were hesitant to join the study. It may also be possible that the caregivers who refused to participate in the study were more engaged in caring for their children, and if that is true, they may have provided more valuable data if they had agreed to participate.

### Conclusion

Findings from this study may have implications for improving the lives and wellbeing of the caregivers by offering an environment and facilities where the persons with DS are supported to fulfil their context specific needs. Although caregivers accept the diagnosis of DS in their children after initial shock and struggle, we recommend an empathic and supportive care and counselling mechanism for the parents of newly diagnosed children with DS. As the caregivers' mental wellbeing suffers heavy toll of tirelessly caring for the persons with DS, where they sacrifice their social lives and careers, it is crucial to support them with interventions tailored to their circumstances. Parents need support in establishing an optimum environment for the persons with DS where they can acquire quality education and freely participate in social activities. Lastly the

healthcare services for the persons with DS need to be further streamlined to prevent stress of seeking a range of advanced laboratory tests and treatments from a variety of facilities and providers.

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### Disclosure statement

No potential conflict of interest was reported by the authors.

### ORCID

Jamil Ahmed  <http://orcid.org/0000-0002-3635-7912>

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