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Abstract

Introduction: Parenting a child diagnosed with autism spectrum disorder (ASD) is challenging for mothers because of concerns related to behavior, difficulties in accessing specialized care, and lack of community acceptance, yet their stories in Jordanian context are still unknown. Common challenges in Jordan include financial burdens, lack of public awareness, and lack of specialized knowledge even among health care providers, which may lead to delays in obtaining the diagnosis and interventions for ASD. **Method:** A phenomenological descriptive approach was used to explore and understand the mothers' everyday lived experiences of raising a child with ASD. Semistructured interviews were conducted with 14 mothers to identify their challenges so that nurses can identify gaps in services, empower families, and facilitate optimum care to these Jordanian families. **Findings:** The main themes that emerged were (1) mothers' journeys with the diagnosis, in which mothers recognized the abnormalities of their children, reported delays in getting the diagnosis and initiation of treatment, and described a wide range of reactions to the diagnosis from grief and guilt to a blessing from God; (2) the burden of care, by which mothers reported physical and emotional exhaustion, financial burdens, and concerns about the quality of available services; and (3) the consequences and the hurdle of having a child with ASD, which affected the family relationships and social life. **Discussion:** Jordanian mothers caring for children with ASD face several challenges, including physical, psychological, financial, and social challenges, in addition to limited specialized services. Identifying their unique challenges and needs are essential to support them, provide appropriate services and resources, and develop policies and guidelines for culturally competent quality services.

Keywords

autism spectrum disorder, child, Jordan, mothers, qualitative, phenomenology

Introduction and Background

Parenting a child diagnosed with autism spectrum disorder (ASD) is challenging for parents. ASD is a pervasive neurodevelopmental disorder that is characterized by impairments in social communication, and, restricted, repetitive patterns of behavior, interests or activities (American Psychiatric Association, 2018). These children struggle with communicating and may cry or scream to express their needs, posing difficulty for parents both inside and outside the family environment (DePape & Lindsay, 2015). Such behaviors can be overwhelming to the caregivers, particularly, mothers because they are usually the primary caregivers (Miranda et al., 2019). Culturally, mothers are the primary caregivers for children in Jordan, yet the stories, challenges, and needs of mothers who care for children in Jordan are still unknown. The purpose of this study was to describe the experiences of

mothers caring for a child with ASD and identify challenges they encountered so that nurses can identify gaps in services, empower families, and facilitate optimum care to Jordanian families.

Personal characteristics and cultural backgrounds can influence the mothers' responses to stressors (Lee & Fong,

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2018). Acceptance during periods of crises, for example, is linked to obedience with submission to God in the Muslim faith (Achour et al., 2016). In addition, the paternalistic nature of Jordanian culture expects men to be breadwinners and mothers to be caregivers and nurturers (National Council for Family, 2018). Such family dynamics assumes that mothers will manage chronic conditions as well. Therefore, mothers in the Arab world may experience increased physical exhaustion, resulting from constant caregiving to the sick, nurturing the children, and household chores. Despite the small percentage of working mothers in Jordan (International Labour Office, 2018), being employed may add another layer of stress to their role as mothers.

Understanding their unique experiences and their stressors may help health care professionals to support them to cope more effectively, which in turn can impact both mother and child's health and quality of life. Understanding the unique challenges and needs of mothers who care for children with ASD may help nurses to develop programs, resources, services, and strategies to empower these mothers thereby increasing their self-esteem, self-efficacy, adequacy, and ability to control stressful situations (Weiss et al., 2015). As parenting stress may negatively impact the effectiveness of interventions for children with ASD (Estes et al., 2019), helping mothers will ultimately help children. A relaxed parent can set the atmosphere of peace and safety for the child and equip the parent to be efficient in meeting the child's need.

ASD: The Magnitude of the Problem in Jordan

The incidence and prevalence of ASD are on the rise (WHO, 2019). The most recent statistics indicated that 1 in 59 children in the United States is diagnosed with ASD (Baio et al., 2018) and the overall prevalence in Asia, Europe, and North America combined come to 1% to 2% (Centers for Disease Control and Prevention, 2013). In Jordan, actual data that reflect the incidence and prevalence of ASD are unavailable. However, a retrospective study involving a Child Neurology Clinic in Jordan indicated that about half ($n = 229$) of the children diagnosed with Global Developmental Delay (GDD) have an ASD (Masri et al., 2011). A major challenge, in Jordan, is the lack of awareness about ASD leading to a delay in diagnosis (mean age at diagnosis = 3.8 years; range = 14 months to 9 years; Masri et al., 2013). Delay in diagnosis could be due to a lack of screening tests for ASD in Jordanian hospitals and a lack of knowledge among health care providers (Masri et al., 2013). In addition, in Jordan, a middle-income country, mothers may face financial burden, and need to fulfill employment and family responsibilities, which can affect maternal psychological status (Dardas & Ahmad, 2014). The ministry of social development runs 109 special education institutions and centers in Jordan (governmental, private, and nonprofit) that provide educational programs and services for people with autism (Shkokani &

AlSmadi, 2018). However, the number of governmental centers to diagnose ASD is limited due to a shortage of trained and qualified staff, which negatively affects the accurate diagnosis of the disorder (AlBayan News, 2013). Specialized educational services are also limited in Jordan (Rayan & Ahmad, 2018; Dardas & Ahmad, 2014). These services are not only limited to Jordanian patients but also for other nationalities who live in Jordan. As a result, these centers and institutions provide services for a small percentage of children with ASD. While a few studies in Jordan examined the incidence, prevalence, and age at diagnosis of ASD, the experiences of families that care for children with ASD are not found in literature. Understanding the experiences of these mothers may help health care providers to improve appropriate services and enhance access to these services, which can help reduce stress and enhance their well-being (Dardas & Ahmad, 2014; Samadi & Mcconkey, 2014).

Literature on families that care for children with ASD is abundant in the context of Caucasian families in the West (Corcoran et al., 2015). However, there is less literature about family care of children with ASD from the African American culture. Some researchers have examined the cultural care of African American children with ASD identifying cultural influences that can delay the diagnosis and subsequent treatment of children with ASD. These influencers included HCP bias, poor health care access, parental knowledge of ASD, and a stigma of disability (Burkett et al., 2015). Such information is scant in the context of Jordanian families. Disorders such as ASD carry a stigma in Jordan (Dardas & Simmons, 2015), which may make Jordanian parents delay seeking health care for these children. Therefore, it is essential to explore the challenges and needs of Jordanian mothers who care for their children with ASD, their physical, mental, psychological, social, and financial burdens to better facilitate adequate and effective interventions. The research question that guided this study was, "What are the Jordanian mothers' experiences in caring for a child with ASD?"

Method

Design and Setting

A phenomenological descriptive approach was used to explore and explain the mothers' daily lived experiences and sufferings when raising a child with ASD. This approach was appropriate because it described real-life stories and explored the difficulties that are faced by mothers of children with ASD. Additionally, it provided a view of the maternal emotional experiences that came with the diagnosis of a child with a serious disease (Gona et al., 2016).

Sample

Fourteen mothers caring for children aged 4 to 14 years diagnosed with ASD were interviewed and were asked to

Table 1. Sociodemographic Characteristics of Mothers.

Mothers' initials	Mother's age (years)	Number of children	Mother's level of education	Monthly income (US\$)	Child with ASD age (years)
EK	45	4	Diploma	635	5
EQ	34	3	High school	350	4
EL	27	3	Diploma	565	4.5
EA	43	3	Baccalaureate	1,410	9
EO	40	5	Diploma	380	9
EA	36	2	Diploma	280	4.4
EI	34	4	Baccalaureate	700	7
EM	36	3 twins	Diploma	845	9
EH	30	4	Diploma	425	4
ED	38	3	High school	280	7
EMO	40	6	High school	425	7
EAY	49	4	High school	450	14
EOQ	30	6	High school	1,130	10
ER	30	3	High school	425	12

Note. ASD = autism spectrum disorder.

disclose their experiences and needs. Purposive sampling was used to recruit these mothers from an outpatient psychiatry clinic in Jordan. Inclusion criteria consisted of Jordanian mothers, who are fluent in Arabic, and have at least one child diagnosed with ASD. Mothers' age at interview ranged from 27 to 49 years and the age at which the children were diagnosed with ASD ranged from 2 to 4 years, with a mean age of 2.6 years. The age of children at study time ranged from 4 to 14 years (Table 1). Of the 14 children, 12 were males and two were females.

Data Collection Procedure

Approval from the institutional review boards (IRBs) of the involved parties were obtained prior to data collection (IRB No. 14/115/2018). Participants were identified from the admission register in an outpatient psychiatric clinic. All mothers approached by the primary nurse researcher were interested in participating in the study. Written consents were obtained for participation. Data were collected using semistructured face-to-face interviews. All the interviews were conducted in Arabic by the primary researcher. Each interview lasted for an average of 60 minutes. Saturation was reached when no new information was forthcoming in the interviews and the data collection process ended.

Mothers were asked to respond to the main open-ended question, "Tell me how you felt when you learned that your child had autism." Follow-up questions were asked when clarification or further elaboration was needed. An interview guide (Table 2) was developed by the research team and was used to direct the dialogue. The questions were modified based on the preliminary analysis of the first few interviews, where potential misunderstanding and awkward questions were clarified. The guide included demographic questions

about the participants and their children, as well as, open-ended questions regarding the participants' experiences of mothering a child diagnosed with ASD. Probing questions were asked when additional information and clarification were needed on a particular topic depending on the participant responses.

The interviews were audio-taped. All audiotapes were transcribed verbatim in Arabic and coded to safeguard anonymity and confidentiality of the participants' data. Pseudonyms were provided for the participants to protect their privacy. Only the primary researcher knew the identity of the participant and pseudonyms were used for all documentation. After transcription in Arabic, the documents were translated into English and were verified independently by two professors fluent in Arabic and English. Data were stored in a password-protected computer and hard copies were stored in a secure cabinet in the primary researcher's office.

Data Analysis

Thematic analysis (Nowell et al., 2017) was performed after the transcripts were read and re-read to gain familiarity with their contents. The entire transcript for each interview was divided into meaningful units and labeled with codes. The meaningful units were given descriptive codes to identify keywords, categories, and themes. The different codes were then compared based on differences and similarities and sorted into categories and themes. Both the primary researcher and her advisors were involved in the coding and identifying the themes. To ensure the rigor of the analysis process, two qualitative researchers not involved in the data collection were consulted to create a review. The research team then examined each category and created more discrete descriptive subcategories for the contents of each category.

Table 2. Interview Guide.

Interview guide

At the beginning of interview, identify demographic details of the mother including: age, marital status, level of education, employment status, socioeconomic status, number of children (normal and with ASD), and age of child with autism.

Opening question:

“Tell me how you felt after you know that your child is diagnosed with ASD”

Follow-up questions:

1. Tell me about the symptoms your child had prior to the diagnosis?
2. How and when did the correct diagnosis happen?
3. Tell me about your reaction when you knew the diagnosis of your child?
4. How did your family members react to your child condition?
5. What stressors, if any, have you experienced raising a child with an ASD? Can you describe the strategies you have found most effective in dealing with these stressors?
6. Have any strategies been ineffective?
7. Have you received support from anyone in this situation, tell me about it?
8. Did you have to leave work and sit at home because of your child's situation?
9. What are the sources you use to get information about this disorder and how to deal with it?
10. How does having a child diagnosed with ASD affect your family planning?
11. How is the relationship between the autistic child and his siblings?
12. Was your autistic child watching TV and cartoon channels? And for how long?

Note. ASD = autism spectrum disorder.

Table 3. The Study Themes and Subthemes.

Themes	Subthemes
1. The mothers' journey with the diagnosis	<ul style="list-style-type: none"> • Recognition of early signs of ASD • Delay in diagnosis and initiation of treatment
2. The burden of care	<ul style="list-style-type: none"> • Reaction of mothers to the diagnosis • Physical and emotional exhaustion • Financial burden
3. Consequences and hurdles of having a child with ASD	<ul style="list-style-type: none"> • The qualities of available services to the children • Effects on the family • Effect on social life

Note. ASD = autism spectrum disorder.

To enhance neutrality and to ensure trustworthiness of the data, member checking was achieved.

Findings

Three major themes and nine subthemes (Table 3) that captured the essence of Jordanian mothers' experiences of caring for a child with ASD emerged. The main themes include (1) the mothers' journey with the diagnosis, (2) the burden of care, and (3) consequences and the hurdles of having a child with ASD. Under each theme there were subthemes that emerged from our analysis.

Theme 1: The Mothers' Journeys With the Diagnosis

The first theme that emerged was the mothers' journeys with the diagnosis of ASD in their children. The three subthemes include recognition of early signs of ASD, delay in diagnosis

and initiation of treatment, and the reaction of mothers to the diagnosis itself.

Recognition of Early Signs and Symptoms of ASD. Most of the mothers have a strong concern that something was not right with their child long before the diagnosis. The mothers described noticing the limited social interaction and lack of communication skills in their children; however, they attributed this to hearing problems that needed medical consultation. They believed that this speech delay could be resolved with time and never considered it as a sign of ASD. A few mothers suspected a problem with hearing or a delay in pronunciation, while two mothers anticipated that their child had ASD due to family history, one mother said,

At first I thought that my daughter did not hear well and so I took her to the hospital to do a hearing test. The hearing test was quite proper, but they told me that my daughter had autism symptoms.

The mothers knew that something was wrong with their child and sought care from their health care provider, but reported that they lacked knowledge of primary symptoms of autism prior to their child's diagnosis. This lack of knowledge potentially delayed seeking help.

Delay in Diagnosis and Initiation of Treatment. Although the mothers have reported noticing some uncommon behaviors and delays in certain developmental aspects of their children, they did not attribute these to autism as a possible cause, which delayed in requesting medical advice for their children. One mother said, "what I knew about autism is that a child is still sitting only in the corner. We were not aware of many signs." Another stated, "At first, we thought that she could have a hearing problem, then we thought that it might be a problem with her tongue, or with her eyes. We never thought of autism." Not only the lack of knowledge among parents may cause a delay in seeking help, but in some cases the delay in diagnosis occurred even though mothers presented concerns to their health care providers. However, the health care providers did not validate parental concerns about the symptoms of autism and gave false reassurance. Sometimes these concerns were dismissed as psychiatric problems and at other times they were told that the child will grow out of it. These responses led to delayed diagnosis, which resulted in subsequent delay in initiation of treatment. For example, one mother said,

I started noticing that there is something wrong when she was a year and a half old. I thought it was a hearing problem. But hearing tests were normal. The nurse who did the test advised me to go to a psychiatric clinic because she thought that it might be a psychiatric problem. I took her to a psychiatrist in the same hospital, but he told me that my daughter is 100% normal. But the problem remained, and we returned after a year to a doctor in Al-Medina hospital, where they finally diagnosed her with autism.

The Mothers' Reaction to the Diagnosis. The mothers described their reaction to the diagnosis as feelings of sorrow, sadness, shock, silence, crying, denial, guilt, and fear. Some mothers also were shocked and cried profusely the first time they learned about the diagnosis. Three mothers reported that they reacted with continuous crying on confirmation of the diagnosis. Some mothers blamed themselves, and sometimes others:

The feeling is indescribable to anyone. They did not tell me that my son was autistic but they told me that he was suffering from a neurological disorder. It was a very bad feeling. I hope that no one feels what I felt. His father and I felt sorrow and sad for him.

Other mothers reported guilt feelings and believed that something they did might have caused their child's illness such as long periods they let their children watch TV, or them having to work for long hours. For example, one mother

believed that leaving her child for a period of 6 months to join her work was a reason for developing ASD. She stated, "I felt guilty and blamed myself because I left him for three months when he was only six months, an age where he started talking." Another mother believed that letting her twin children watching TV for long periods was the cause:

A television channel was the reason for autism in my child because when I gave birth to them we were moving to another apartment and because of that I used to put them in their room on their own and then I turn the TV on to that channel for almost a year.

Having a child with ASD created a state of fear among mothers about their child's health status, their future, and concerns on how to deal with their child's behaviors. Also, they wondered if there is a cure for this disorder or not. This was evident in their quotes; for example, one said, "I am scared about my child's future, I think a lot about his education, marriage, and about how he will be able to manage himself to meet his basic daily needs."

Although having a child with ASD within the family was described as difficult by all mothers, a few of them described having a child with ASD as "a gift from God." A 43-year-old mother of three children said, "My husband and I were shocked at the beginning, but now we think of him as a gift from God and we thank God for this gift." These mothers talked about the reward of patience, and how having this child gave them meaning and value to their lives.

Theme 2: The Burden of Care

The mothers faced many challenges and concerns associated with care provision of a child with ASD, including physical exhaustion, financial burdens, and concerns about the quality of services available for their children.

Physical and Emotional Exhaustion. Mothers expressed feelings of the increased burden of care with increased involvement and responsibilities in meeting the daily needs of the child with ASD, ongoing management, and follow-up care. The children needed constant supervision that disturbed the mothers' sleep pattern and resulted in their exhaustion. Most of them had to give up their social activities or employment that required attention and energy, to effectively care for the child's changing needs. The increased demands on their physical health and lack of respite or personal freedom were expressed by mothers. Attempting to fulfill their responsibilities of child care along with the other family responsibilities multiplied the burden felt by mothers. One of participating mothers described an increased burden of caring for her 7-year-old daughter:

She still wears diapers; she cannot go to the toilet. Even eating, she has so far not eaten by herself and I still feed her. She is not the only one who needs my help, I have 3 other children and I

am already strained with so much housework, my mother and my mother in law are old and they cannot help.

Such constant care resulted in emotional exhaustion as well. They were consumed in the care of their child, while fulfilling the role of a mother in a Jordanian family context. They felt lonely, helpless, and drained of energy. Lack of sleep and lack of respite and expending their energy for the child and the family exhausted the mothers mentally and emotionally too.

Financial Burden. Most of the mothers reported a financial burden resulting from having a child with ASD. Mothers attributed the financial burden to costs associated with transportation, hospital admission, special diet, and fees for specialized care centers, which exceeded their financial ability. Some mothers had to leave their jobs in order to look after their children. Regular day care centers in Jordan do not accept children with special needs and the specialized centers are too expensive. One mother said that “it was financially difficult to travel to the capital city every two weeks to receive medical services” for her daughter. Another mother said, “The costs were very high. When I hired a special teacher to the house, my parents felt that I struggle financially, they insisted to pay the cost of the special teacher.”

Despite expensive services, the mothers reported a lack of any financial support from governmental or nongovernmental agencies to cover day-to-day expenses incurred. Some families could not afford the cost of private educational centers for children with ASD and were forced to keep their children home. Other families used all their savings and borrowed money to pay for some services:

We accumulated a debt sum of six hundred dinars (\$800) for an autism center and that was a huge amount of debt on us. There is no social or financial support and the Social Development Foundation has been paying for [my daughter] for a very short period of time, although we have submitted for them four years ago.

The Qualities of Available Services to the Children. The ASD centers of the Ministry of Social Development provide free services to children with ASD, however, the number of these centers is limited. Therefore, most families were obligated to use private centers. Mothers' views varied on the usefulness of these centers. Some mothers believed that their children should be integrated with other children in all grades, irrespective of their age, behavior differences, or mental disabilities. Conversely, others expressed concerns about how such integration can negatively affect their children instead of helping them, and indicated the importance of separating children with autism from their peers with mental retardation. A mother of a 9-year-old child with ASD stated, “I put my son in the autism center for only two months and then pulled him out because he began imitating the bad and

hurtful behavior he saw.” Another mother said, “This center puts autistic children with other children with severe mental disabilities and this negatively affected the attitudes of my daughter because she has mild degree of autism.”

Mothers also reported concerns about the high expenses of these centers and the lack of standardization of care, or teachers' qualifications that make the centers less efficient. While there is no data or research available about the services provided for the children with ASD and their families in Jordan, the mothers believed that staff at the ASD centers are not properly educated or trained to deal effectively with their children's needs. Mothers also stated, “not only had I expected them [staff] to help teach our children, but also they should be a source of support for us, and help us find alternative sources of financial support.” Another mother stated, “Private centers are very expensive, and there is a disparity in the cost of treatment between one center and another, which makes us confused about which center is better in terms of quality of care?” The high expenses that these mothers reported, and their beliefs of the inefficiency of autism centers may force families to seek less exemplary but financially reasonable care.

Theme 3: Consequences and the Hurdle of Having a Child With ASD

Mothers reported several consequences of having a child with ASD. The subthemes include effect of having a child diagnosed with ASD on the family and their social life.

Effect on Family. Having a child with ASD impacted the whole family and influenced their psychological and social well-being. Some mothers described how having a child with ASD has strengthened their marriage as it brought the spouses together. Some mothers reported that they were emotionally and physically supported by their husbands, while others felt that their marital relationship was strained by having to take care of a child with a disability.

One mother stated, “he became more sympathetic and always gives me a hand in everything, he takes care of the other kids.” On the other hand, six mothers reported that their marital life became strained which increased the stress and tension of mothers:

My anxiety, tension, nervousness and frustration have greatly reflected on my attitudes with my other kids. And when they wanted to go outside and play, I refuse to let them do that without taking their brother with autism with them.

Mothers were often forced to focus most of their attention on the child with ASD, which caused some siblings to “feel jealous,” or to bear more responsibilities. The needs of the child with ASD took priority and the whole family's activities revolved around the sick child. The siblings' feelings

toward their sibling with ASD varied between loving and caring behaviors, feelings of discomfort because of their violent behavior, and stress from more responsibility of looking after their sibling with ASD entrusted by their parents, “Even his siblings; when we go out to any place I feel sad for them because they cannot play with other children as they have to keep an eye on their brother.” Another mother said, “His brothers love him a lot but at the same time they feel that he is restricting their activities.”

Effect on Social Life. According to the mothers of this study, they faced social stigma manifested by criticism and stereotyping attitudes from other people that include other family members, neighbors, strangers, and friends. This stigma was related to their children’s behaviors which include twirling and tantrums, socially inappropriate, disobedient, and disruptive behavior. Mothers were blamed for their children’s social and behavioral problems. They were criticized for their inability to control their children’s behaviors. They isolated themselves outside their close family members because of the negative comments and lack of support from the community, compelling them to avoid social events. One mother said,

I do not like to talk about my child’s situation in front of other people because I am embarrassed that my son is autistic. I know that this is something from God, but I feel humiliated because of the people’s questions about his behavior and tantrums, which are very curious and embarrassing.

Another mother stated,

I started to hate going out of the house or to sit and communicate with other people, not because of my child’s situation, but because of society itself; it is self-centered and disgusting.

Discussion

The purpose of this study was to understand the experiences of mothers caring for a child with ASD and identify their challenges and strengths. Our findings suggest that, in the prediagnosis stage, mothers were aware of the signs of atypical patterns of development of their children and experienced an uncertainty about their children’s growth, cognitive abilities, and behaviors when compared with children without ASD. The uncertainty pertained to the atypical growth and abnormal behaviors of their children or the belief that these behaviors will disappear someday, and the child will be normal. Similar concerns of developmental delay or motor impairments were reported in a recent study of Egyptian mothers of children with ASD (Gobrial, 2018). In addition, feelings of uncertainty among Taiwanese parents of children with ASD were described in a previous study as “exhausting” and “very stressful” (Chao et al., 2018). The majority of mothers suffered from anxiety because their child did not develop or behave like other children. They reported

confusion and doubt about the seriousness of the problem instead of accepting the fact that their children need medical attention. Many mothers were in denial as they ignored the symptoms of autism and denied any possibility of a medical condition in their children.

Furthermore, families believed that the passive reassuring responses of health care professionals to early concerns expressed by parents regarding a possible delay in the child’s development led to a delay in diagnosis and treatment. This finding is consistent with the findings of Matenge (2012), who reported similar delays in obtaining a formal diagnosis of ASD in Nigeria in which parents’ concerns were considered as excessive anxiety. Similar finding was also reported in a Canadian study, which indicated that the delay in diagnosis caused much frustration for parents who knew that something was wrong with their children, and as a consequence, this led to a delay in accessing appropriate services (Hoogsteen & Woodgate, 2013). Other research indicates that when health care providers do not respect the parental knowledge of their child, this may delay seeking or obtaining services (Burkett et al., 2015).

Several mothers in our study expressed guilt as they reported that they allowed their children to watch TV and cartoon channels at a very early age for prolonged periods of time while they finished the household chores. Some mothers put blame on television for being the cause of ASD. Lin et al. (2015) reported that young children who watch television for a daily average of 67.4 minutes before the age of 2 years, have the risk of delayed cognitive, language, and motor development (Lin et al., 2015). Others reported that allowing early exposure (<2 years old) to the electronic screen also can affect language development and cause autistic-like behavior, short attention span, and speech delays possibly due to its effect on the central nervous system (Hermawati et al., 2018).

Mothers in our study expressed concerns and fear about the future of this child with ASD. Their fears included: education, independence in activities of daily living, the possibility of married life, movement around their house without help, and impact on their siblings. Similar concerns about uncertain future and unpredictable behavior resulting in increased parenting stress were found in the literature (Li & Lo, 2016). Mothers are often uncertain whether their children will be able to live independently in the future or not (Li & Lo, 2016).

Although it is a difficult experience to have a child with autism, some mothers considered having a child with ASD as a gift from God, which gave them meaning and value to their lives. In our study, 13 out of 14 of our participants were Muslims. In Islam, the misfortune of having a child with a chronic illness, is believed to be an atonement for a person’s sins. Acceptance and patience during periods of crises are linked to devotion to God and considered a step to heaven in the Muslim faith (Achour et al., 2016). This concept of a gift of God is supported in other cultures also, in which African

American parents believed that they were blessed to care for a child with ASD (Burkett et al., 2017)

Mothers reported experiences of physical exhaustion as they try to balance their routine for the whole family in addition to meeting the demands of care for the child with ASD who requires additional time and effort. They also were frustrated by the lack of time for self-care and overwhelming family demands (DePape & Lindsay, 2015). It was reported that with proper support from friends, support groups, and community or professional resources, mothers felt less isolated, more optimistic, and generally more satisfied with life (Zaidman-Zait et al., 2017). Ten out of 14 mothers were homemakers, which prohibits any time without direct care for the child, deepening feelings of isolation. Other researchers have reported feelings of isolation of single mothers who have sole responsibility to care for a child with ASD (Burkett et al., 2017).

With a monthly family income that ranged from US\$280 to US\$1400 (average of US\$560) for the participating mothers, the financial burden was a recurring theme in our study. Autism rehabilitation centers are cost-prohibitive. Most centers are privately operated and can cost JD400 to JD600 per month (US\$500-800), which exceeds the average monthly income of the majority of Jordanian families. Comparable findings were reported by a previous study where they found the families of children with ASD were more likely from relatively lower income households, while having costly educational expenses (Ou et al., 2015). Families who experienced financial strain may be forced to seek less exemplary, easier, and financially feasible care (Zablotsky et al., 2014). With most of the mothers as homemakers, their income is limited to one parent, thereby placing them in financial strain, which can cascade to emotional and physical exhaustion.

Some mothers in our study believed that having a sick child in the family strengthened their marital relationship, as it brought the parents together. This was also found in Burkett et al. (2017), in which having a child with ASD resulted in more family emotional closeness. A few mothers however, experienced marital problems especially during the stage of diagnosis. High levels of stress and increased workload of caring for the affected child while caring for the whole family negatively impacted their relationships with their husbands. Findings from a systematic review on relationships of parents of children with ASD indicated the need for developing strategies to secure social support, reduce parental stress, and support the development of positive couple relationships (Saini et al., 2015).

Siblings' feelings toward the child with ASD varied; they loved their sibling but were worried because of their behavior. The dual nature of sibling relationships has been described in the literature—it consists of both positive and negative dimensions and emotions. Aggressive behavior from the sibling, and, prejudice and negative reactions from other people leading to feelings of embarrassment among the healthy siblings can affect sibling relationships (Angell et al., 2012).

Mothers of children with ASD faced different types of public stigma, primarily directed to these children themselves because of their behaviors, which may adversely affect them and cause them to feel neglected or excluded (Chan & Lam, 2018). Mothers might develop self-stigma as they internalize negative self-thoughts, which may affect negatively their self-esteem and self-efficacy and affect their psychological well-being (Chan & Lam, 2018).

Implications and Recommendations

Personnel and public education about ASD are vital to raising awareness. Sharing information about the early signs of ASD on a regular basis is essential for raising public awareness. Information can be shared through the media or through community meetings held in malls or schools during public outreach campaigns. Health care providers and social workers should be trained adequately to provide evidence-based care for children with ASD and for helping these families with support and information. Services should target improved maternal psychological well-being, and, child development and well-being.

Services for ASD is an emerging need in Jordan. These services are not defined well and the staff in the current centers do not have any special training, to our knowledge. In the past, children with chronic illnesses were considered a “gift or curse from Allah” and were cared for at home and because of the stigma people never took these children out anywhere even to health care facilities. In our study, six of the 11 children were diagnosed after their fifth birthday, although several mothers had “concerns” about their children’s development. Health care providers and nurses can actively listen to families and help advocate for them with physicians or others when discussing their frustration level with being “passively reassured.” These findings emphasize the need for improving health care services for families raising children with ASD, and increasing the number of specialized trained providers. This will help in early diagnosis, reduce waiting times for appointments, strengthening physician–patient contacts, supporting parents’ decision-making processes, increasing care coordination, and improving health care coverage, which can reduce financial stress.

Limitations

The sample consisted of Jordanian mothers raising children with ASD. Therefore, the experiences of these mothers may not be the same as those in other Middle Eastern countries or cultures, however, as these cultures share similar language and religion, the findings of this study may be transferrable to similar contexts and cultures. Others can learn from our experience and can explore the experiences unique to the parents who care for children with ASD. In addition, with several Jordanians working outside the Middle Eastern region, knowledge of these experiences may be transferrable at the point of care they encounter.

Conclusions

This study provides a picture of the perspectives and experiences of mothers who raise a child diagnosed with ASD and sheds light on the range of their feelings, thoughts, fears, and difficulties. All the mothers in our study experienced physical, psychological, financial, and social burdens. Mothers in the current study reported negative reactions to the diagnosis such as shock, sorrow, denial, crying, stress, guilt, despair, inferiority, and loss. Moreover, the grief over the loss of normal life and development for their children with autism as well as the increased daily needs of their children were expressed. The participants shared the same Islamic faith. This is an important finding that many felt the grief and loss and others found the child to be a gift of God. The study also points out the mothers' perception of the support provided by the available private centers. Relationships within the family members were affected, therefore, special attention must be paid to sustain healthy relationships within the family, particularly among siblings, to avoid feelings of resentment and competition for attention. Identifying the unique challenges and needs of mothers of children with ASD is essential to support them, provide appropriate services and resources, and develop policies and guidelines for culturally competent quality services.

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Supplemental Material

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