

Case-Based Insights: Arab Muslim Mothers' Experiences of Managing a Child Newly Diagnosed With Type 1 Diabetes Mellitus

SAGE Open Nursing
Volume 5: 1–12
© The Author(s) 2019
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/2377960819870979
journals.sagepub.com/home/son



Rachel Cathrine Rossiter, HlthScD¹ , Jennifer Louise Cooper, DPubHlth², Suhad Issa Marjei, BSN³, and Sharon Brownie, DBA⁴

Abstract

Mothers frequently fulfill the role of primary caregiver for children diagnosed with type 1 diabetes mellitus (T1DM). A T1DM diagnosis has a significant impact on the child and the wider family unit. The objective is to develop understanding of mothers' experiences caring for children diagnosed with T1DM in the cultural context of the Middle East to facilitate enhanced health service provision and support. This study used a qualitative design. Data were collected in individual semistructured interviews. Participants were mothers of Arabic descent and Muslim belief who had a child diagnosed with T1DM within the last 12 months. All mothers were registered at the health service where this research was conducted and resident in the United Arab Emirates at the time of this study. COREQ guidelines informed reporting of the research and findings. Participating mothers described initial reactions of shock and disbelief, followed by transition to *near ordinary* and *near normal* (85% normal) family functioning. Family, culture, and faith emerged as critical supports in the *whirlwind daily challenge* of balancing the multiple demands and competing needs of the newly diagnosed child and the broader family. This study is the first of its kind from countries comprising the Gulf Cooperation Council. The findings provide insight into the challenges and support needs of mothers caring for children newly diagnosed with T1DM in an Arab Muslim context. The findings also provide a basis for enhancing health service support and suggest themes to inform further research.

Keywords

type 1 diabetes mellitus, child services, qualitative research, transcultural

Date received: 12 December 2018; revised: 4 July 2019; accepted: 28 July 2019

Introduction/Background

Type 1 diabetes mellitus (T1DM) is a chronic disease requiring complex daily management. The impact of a T1DM diagnosis on a child and their family is substantial. The International Diabetes Federation (IDF) Atlas (8th edition) estimates that there are 1,106,500 children globally with T1DM (International Diabetes Federation, 2017). In the six Middle Eastern countries comprising the Gulf Cooperation Council (GCC), the absence of accurate data sets makes it difficult to quantify the current prevalence of T1DM among the region's indigenous and expatriate populations (Sarant, 2014). However, the IDF Atlas estimates 175,800 children (aged 0–19 years) in the Middle East and North Africa Region have T1DM, with 0.43 per 1,000 people being in the

United Arab Emirates (UAE; International Diabetes Federation, 2017).

T1DM is an autoimmune disease where the body's own immune system attacks and destroys the

¹School of Nursing, Midwifery & Indigenous Health, Charles Sturt University, Orange, Australia

²School of Health & Social Development, Deakin University, Geelong, Australia

³Sheikh Kalifa Medical City, SEHA Health Services, Abu Dhabi, UAE

⁴School of Nursing and Midwifery, Aga Khan University, Nairobi, Kenya

Corresponding Author:

Rachel Cathrine Rossiter, School of Nursing, Midwifery & Indigenous Health, Charles Sturt University, 346 Leeds Parade, Orange, New South Wales 2800, Australia.

Email: rrossiter@csu.edu.au



insulin-producing beta cells in the pancreas. A child may be diagnosed with T1DM within the first few months of life. However, the majority (>85%) are diagnosed before the age of 20 with a marked peak in diagnosis between the ages of 10 and 14 (Frese & Sandholzer, 2013). Twenty-five percent of those with T1DM are diagnosed as young adults or adults (Maahs, West, Lawrence, & Mayer-Davis, 2010). Management of T1DM requires lifelong insulin replacement therapy via an insulin pump or subcutaneous injection multiple times a day (Brinkman, 2017). If not managed correctly, long-term complications include retinopathy, neuropathy, cardiovascular disease, foot damage, and kidney difficulties (Brinkman, 2017). Problems with thyroid function are also associated with T1DM (Brinkman, 2017).

Review of Literature

T1DM diagnosis has widespread implications for both child and family. Many studies have described the experiences of parents and families caring for a child with T1DM. Parents in the Netherlands reported feeling overwhelmed as they sought to accept a diagnosis of T1DM and learn the complicated skills and routines required (Boogerd, Maas-van Schaaaijk, Noordam, Marks, & Verhaak, 2015). Management of T1DM confronts parents with dynamic and ongoing processes that are both complex and difficult to master. A group of American parents whose children had been diagnosed between 4 and 11 years prior to being interviewed reported still struggling to master the fluctuations of T1DM (Smaldone & Ritholz, 2011). In contrast, Welsh parents, whose children had lived with T1DM for 7 to 10 years felt that they had mastered the daily management required; however, grief, guilt, and anger continues to emerge at times (Bowes, Lowes, Warner, & Gregory, 2009). For parents in Winnipeg, life with T1DM was described as seeking to achieve balance between protecting their child and enabling the child to “be like everyone else” (Nurmi & Stieber-Roger, 2012, p. 530). This pursuit for normality was also described by English parents and children living with T1DM. Although T1DM results in disruption, change, and adapting to “a potentially life-threatening illness,” each person endeavored to achieve a “normal life” (Marshall, Carter, Rose, & Brotherton, 2009, p. 1709). Swedish families interviewed 1 year after their child was diagnosed with T1DM spoke of life as “ordinary yet different,” particularly disrupted at times when blood sugar levels fluctuated with a negative impact on the whole family (Wennick & Hallström, 2007, p. 299).

The qualitative findings in the papers reviewed above present a picture of caregiving that is relentless and physically, psychologically, and emotionally burdensome. Polish researchers administered the Caregiver's

Burden Scale (Macera, Eaker, Jannarone, Davis, & Stoskopf, 1993) to identify specific factors that affected the level of burden of caregivers experienced by parents of children with T1DM (Kobos & Imiela, 2015). Overburdening was associated with factors such as being the sole caregiver, isolation, lower educational level, and economic status. Caregiver burden has been identified as multidimensional phenomena, subject to change and influenced by factors such as characteristics of the caregiver, the demands required, and the level of involvement required (Chou, 2000). Chou's Model of the Caregiver Burden defines burden as “an individual's subjective perception of overload in one or more perspectives: physical, psychological, social and financial” (p. 405). Caregiver burden has become a widely researched outcome largely measured by quantitative measures. However, Bastawrous (2013) urges against a reliance on such measures and recommends the inclusion of qualitative data to “capture important contextual elements of the caregiving experience” (p. 432).

Most studies describing family or parental experiences of caring for a child with T1DM were conducted in Western settings, including the United Kingdom (Marshall et al., 2009; Rankin et al., 2014), United States (Rearick, Sullivan-Bolyai, Bova, & Knafl, 2011; Rechenberg, Grey, & Sadler, 2017; Smaldone & Ritholz, 2011; Whittemore, Jaser, Chao, Jang, & Grey, 2012), and Australia (Thorsteinsson, Loi, & Rayner, 2017). In some countries, a young child's mother becomes the primary person responsible for disease management until the child develops the maturity and capacity to self-manage (da Cruz, Collet, de Anrade, da Nobrega, & da Nobreg, 2017; Kobos & Imiela, 2015). However, studies focused specifically on mothers' perceptions, experiences, and the impact of having a child diagnosed with T1DM are limited (Abolhassani, Babae, & Eghbali, 2018; Khandan, Abazari, Targari, & Cheraghi, 2018; Rechenberg et al., 2017; Thorsteinsson et al., 2017).

No studies focused on mothers' experiences of T1DM have been conducted in the GCC region. Although two studies from Iran (Abolhassani et al., 2018; Khandan et al., 2018) examined the experiences of mothers caring for children with T1DM, there are significant cultural, language, and contextual differences between Iran (where the primary language is Persian) and Arabic-speaking UAE. The study reported here reflects the desire of specialist T1DM health service providers in the UAE's largest Emirate (Abu Dhabi) to better understand the needs of mothers in caring for a child during the first 12 months of T1DM diagnosis. Improved understanding in this area will support enhanced service provision. The purpose of this study of qualitative case insights was to elicit in-depth understanding of UAE mothers' perspectives and experiences of having a child diagnosed with T1DM. It also aimed to identify the role

of family, community, and culture during the first months after diagnosis and clarify the role the health-care team play during this period.

Methods

This study used a case-based qualitative descriptive design to explore the perspectives and experiences of mothers whose child had been diagnosed with T1DM. Mothers' perspectives and experiences were captured in semistructured interviews.

Recruitment

Participants were purposively sampled through the T1DM mothers' support group at Sheikh Khalifa Medical City (SKMC), Abu Dhabi. One of the present researchers was responsible for participant recruitment based on specific inclusion criteria. Potential participants were telephoned and invited to participate in the study. Participation rates were low. This was attributed to the heavy time demands on mothers arising from looking after a child with T1DM plus broader family responsibilities, and the inclusion criterion focused on new diagnosis. Five mothers consented to participate. However, one interview was excluded from the analysis because the audio file had not recorded correctly and was incoherent.

Inclusion Criteria

Mothers of Arabic descent and Muslim belief resident in the UAE at the time of the study, who were registered at SKMC with a child newly diagnosed with T1DM (within the last 12 months).

Ethical Considerations

This study was approved by the SKMC Institutional Research and Ethics Committee (REC-10.06.2014: RS-302). SKMC is a major health service provider in the Abu Dhabi Government Health Services Network. All participants provided informed consent to participate in this study.

Sample

Of the five participants interviewed, four transcripts were available for analysis. Although the study inclusion criteria were broad, consenting participants all had tertiary level qualifications in health care (nursing or pharmacy) and thus represent an unexpected, self-selected, and specific subset of possible participants. Participants' characteristics (including pseudonyms) are presented in Table 1.

Data Collection

This study was conducted at SKMC in Abu Dhabi, UAE, in 2015. Participants completed 45- to 60-minute individual interviews at the SKMC diabetes clinic. Conversational questions were used to guide the semistructured interviews (Online Appendix 1). Before commencing each interview, the purpose of the interview was explained to participants (in Arabic). An interview sheet was provided for each participant in their own language (Arabic). Participants were informed that they could withdraw from the study at any time, and confidentiality was emphasized. Researchers obtained permission to record the interview, and participants completed signed consent forms. Interviews were conducted

Table 1. Study Participants.

Mother (pseudonym)	Child		Notes
	Age (years)	Sex	
Khulud	8 years 1st born 3 siblings	Male	Child born in UAE, Mother Qatari Mother's education: Diploma in Nursing Family: T2DM in maternal and paternal grandparent
A'isha	3 years 1st born 1 sibling	Female	Child born in UAE, Mother Emirati National Mother's education: Diploma in Business Management and is a nursing student Family: T2DM in maternal and paternal grandparents with extensive history in aunts and uncles
Fatima	6 years 2nd born 1 sibling	Female	Child born in UAE, Mother Egyptian Mother's education: Pharmacist Family: Maternal aunt has T1DM. Paternal grandparent with T2DM, Sibling has T1DM
Basimah	6 years 5th born 5 siblings	Male	Child born in UAE, Mother Palestinian Mother's education: Nursing and Masters in Health Service Management Family: T2DM in maternal and paternal grandparents

T1DM = type 1 diabetes mellitus; T2DM = type 2 diabetes mellitus.

in Arabic by the Arabic speaking research team member, supported by another (non-Arabic speaking) researcher.

Data Analysis

Yin's (2010) five phases of analysis provided the conceptual framework for the data analysis. Information for analysis comprised audio files from the four Arabic transcripts of interviews included in the analysis, the English translation of each interview and handwritten notes taken by the interviewer. Audiotapes were listened to multiple times, with verbatim transcriptions from *pigeon* Arabic to formal Arabic to English. The Arabic speaking members of the research team reviewed the accuracy of translation and data interpretation. Data were cross-checked by all members of the research team.

Phase 2 of the analysis (disassembling of the data) required extraction of individual responses to each research question from the database. Audiotapes and transcripts were reviewed several times to ensure the content, tone, and accurate capture of participants' feelings. Phase 3 involved extracting significant statements from the disassembled data, and reassembling these statements under the five key areas explored in the interviews. Reassembled data were interpreted in collaboration with members of the research team (Phase 4). The final stage of data analysis (Phase 5) drew together the reassembled data. Data were interpreted to identify an overarching theme, with three subthemes that illustrated the complexity of participants' experiences.

Undertaking the research and data analysis required careful attention to the transcultural nature of the study. Each member of the research team resided in the UAE or had significant experience working in the Middle East. The research team included an Arabic speaking researcher with cultural competence specific to the UAE context.

Results

The analysis revealed an overarching theme *journeying from disbelief and shock to acceptance and patience*. This portrayed a common experience described by participating mothers. Three separate subthemes emerged that illustrated participants' experiences, specifically: *initial impact of diagnoses; what helped; and how it is now*. Verbatim quotations from participants (using pseudonyms) are included to illustrate the findings.

Initial Impact of Diagnosis

Although it was close to 1 year since diagnosis, each mother could clearly recall the experience of initial disbelief and shock following diagnosis. It was a time of

distressing emotions, and the mothers described wide-ranging worry and concern for their child.

...we could not believe this happened...all of us are very shocked, I was very much worried about my son (KHULUD)

[I am]...so upset and confused, I could not believe it, as she is still very young. (FATIMA)

Mothers' psychological distress at the time of diagnosis was evident.

This was not expected to happen to our daughter...[I] cry with bitterness and pain. (A'ISHA)

Initial disbelief and shock progressed to worry and fear, with worry extending beyond the child's current well-being to the child's future, along with fears about others' beliefs about T1DM and the potential impact of stigma directed toward the child. The enormity of the diagnosis was evident, as each participant spoke of their struggle to learn what was required to care for their child. Concerns related to day-to-day management of T1DM, learning to administer insulin, recognizing and managing episodes of hypoglycaemia and ketoacidosis, possible complications, managing the required dietary changes, and monitoring the child's nutritional intake.

Who can I communicate with if he has any issues or is unconscious? (KHULUD)

Daily fears were compounded by fear for the future impacts the child would face as a result of their T1DM diagnosis.

...[and] what about his future? Will he be able to get married? (KHULUD)

I'm so worried about the future...taking insulin all her life. (A'ISHA)

Mothers also identified concerns about stigma associated with a T1DM diagnosis and worried about how this would impact on their child both at present (e.g., at school) and in the future.

I was so worried about the consequences of spreading the news among them, which may have a negative or bad effect on my daughter's future. (FATIMA)

The school was not cooperative in taking care of her health, but after an argument with the school management, the treatment has changed and become much better. (A'ISHA)

For one mother, potential stigmatizing behavior from family members with limited knowledge of T1DM was a particular concern.

I requested my husband to keep this incident confidential and not to disclose it to neighbors or some other relatives, particularly those who are not educated. (FATIMA)

The disruption arising from a T1DM diagnosis was apparent in participating mothers' descriptions. However, each mother identified factors that enabled her to manage this unexpected intrusion into the life of their child and the functioning of the whole family.

What Helped?

Mothers spoke of ways in which faith, family, and culture impacted on their experience, while also mentioning some of the challenges in these interactions.

Faith and Culture

The pivotal role that participating mothers' spiritual connections and faith played in coping with this diagnosis was apparent.

I pray much and do lots of supplications for her. (FATIMA)

My parents keep praying and keep reciting versus of the Holy Quran, and repeating certain supplications to Allah. (BASMAH)

One mother described her faith as providing a way of viewing this situation as one to be accepted without question.

I have a strong faith in Allah, and we as Muslims should surrender to Allah's destiny. (A'ISHA)

Another mother's reference to the antidiabetic benefits of olive leaf was consistent with ancient Islamic and Arab descriptions of the therapeutic benefits of the olive tree (described in the Quran as the *holy tree*; Darimi, 69:103).

It is said that olive leaf helps in reducing the blood sugar to reach normal percentage. (KHULUD)

Nevertheless, some aspects of adherence to the Islamic faith posed challenges for these mothers. The increased focus on religious practice and family that occurs during Ramadan (ninth month of the Islamic calendar), which is observed as a month of fasting, was particularly testing. For a person with T1DM, maintaining recommended dietary intake and meal spacing becomes problematic when others are following the practice of fasting during daylight hours, followed by eating together after dusk in extended family groups with special sweets and foods. Although exemptions from fasting for people with such health conditions and children are clearly stated, Basmah

described her attempts to manage the tension between faith and managing T1DM.

During Ramadan, I encourage them to fast. When we visit peoples' houses I let them take [a] small amount, so they will not feel different than other children. (BASMAH)

Faith and cultural factors with support from extended family generally served to ease the difficulties and disruption of a diagnosis of T1DM.

Extended Family

One mother spoke of how much relatives and friends had assisted her.

We have been supported fully by all relatives and friends, and this support made our life run smoothly and easily. (A'ISHA)

In contrast, another mother described being so overwhelmed by the diagnosis that she kept the situation to herself for some time, resulting in difficulties with her family. However, she suggested that this was resolved and her family provided support that enabled her to manage this disruption.

My family live here in the country and because I didn't tell them early about the incident, they blamed me much. I was very much confused, shocked, and upset of the new situation. In general, yes, I have received full support from my family. (FATIMA)

For these mothers, faith, cultural factors, and family were clearly identified as enabling them to manage in this difficult time.

Health-Care Professionals

Participating mothers identified how health-care professionals had assisted them. The positive impact of contact with physicians, nurse educators, and nurses in clinical settings and schools was evident in mothers' reports of their interactions with clinicians.

I got full support from the ER, the pediatric physician comforted me a lot and made me feel that I'm strong and brave enough to face the new situation. (FATIMA)

One of the health professional supports that helped the most was the treating physician...[who had an] excellent technique and instilled hope in ourselves. (KHULUD)

Of note, the attitudes and behaviors of these health-care professionals were described in terms of giving comfort, instilling hope, gentleness, and cooperation.

The nurses and educator were so good and so gentle.
(FATIMA)
All the medical staff was so cooperative. (A'ISHA)

Education and assistance in learning about the intricacies of managing the daily complexity of T1DM were also valued by participating mothers.

The health education... (A'ISHA)... in relation to the food given and timing of blood sugar testing. (FATIMA)
The school nurses played a major role and helped us a lot. (FATIMA)

Participating mothers also suggested ways in which services could be improved. Suggested improvements related to access to assistance when needed and the availability of supplies.

The quantity of injections needed [were] unavailable in the pharmacy. (KHULUD)
Phoning the clinic and nobody answers. (KHULUD)
For me, I think everything was so perfect, probably the supplies and the medicine if [they] were brought to me, it would be much better than getting it myself as I was alone here in the hospital with my daughter and I didn't like to leave her. (FATIMA)

A need for child-focused teaching material was also highlighted by one participant, who asked for:

booklets with coloring explaining diabetes in a simple way for kids themselves. (A'ISHA)

Although there were some areas of health-care delivery that needed improvement, participants highlighted ways in which these different factors supported them during this disruption and helped them as they developed the capacity to care for their child with T1DM.

And Now

In contrast to the shock, disbelief and confusion experienced on diagnosis, and the multitude of worries that threatened to overwhelm participating mothers, they indicated a significant shift toward acceptance and an *almost normal* life.

But over the time, the situation has been changed and become almost ordinary and acceptable to us. (KHULUD)
I can say the impact of the incident on us, over time became almost normal. (A'ISHA)

Gradually over time, we adapted to the new situation. (BASMAH)

The situation became normal, up to 85%. (KHULUD)
They (family) encouraged me to be optimistic and... they supported me morally and materially... over time the impact of the incident on us became almost normal. (A'ISHA)

Although one participant described *now* as almost ordinary, she was open about the way in which T1DM had impacted on her relationship with her husband and others.

There was an impact on my life personally and on the relation[ship] I have with my husband, who noticed this clearly and told me that I had become nervous and my relation[ship] with him and with others became a little different. (KHULUD)

Another mother noted that her child's T1DM diagnosis had impacted her relationship with her husband.

My relation[ship] with my husband became a little different than before. (A'ISHA)

One mother spoke of the impact T1DM had on her relationship with her daughter, and her increased anxiety and stress as she attempted to manage her behavior.

I sympathize with [my daughter with T1DM]... sometimes I get upset and nervous of her behavior and endless requests. (FATIMA)

In contrast, she described her wider support network as somehow enhanced by this situation.

Our relations[h]ips with our friends in general were so good, and some of them became closer and friendlier to us. (FATIMA)

Two mothers reported that the whole family had adapted to a changed diet.

It has been changed much. (FATIMA)
...we have changed the eating pattern for the entire house. (BASMAH)

Although, these four mothers spoke of life currently being almost normal, almost ordinary and of having adapted to life with a child with T1DM, their responses to what a typical day involved were anything but *ordinary*. Rather, their descriptions of a typical day illustrated the complexities of caring for a child with T1DM.

We wake up in the morning and first thing I check blood sugar before having breakfast. After breakfast, I give the

dose needed and their father usually, takes them to their school. The school nurse takes care during my absence and she keeps in touch with me 2–3 times daily. I get them home from school for their lunch. Before going to bed, I check blood sugar and give the dose needed. I myself, go to bed almost after midnight, when I'm certain that all the tasks have been made. (FATIMA)

Usually, I check my daughter's blood sugar before and after the meals and at frequent times of the day. I prefer to cook at home and in the afternoon, I go to bed with her to get some rest. After I wake up, I check her blood sugar again. If it is low, I usually give her fresh juice. (A'ISHA)

Figure 1 presents the intrusiveness of the necessary management activities.

The vigilance and monitoring required was such that siblings were involved in observation and administration of insulin. Before T1DM diagnosis, each child went to school and the mother was able to rest assured that her child was safe. Frequent contact with the school had now become the norm, and a readiness to drop any other activity became a necessity. Despite the changes required since the participating mothers had learned that their child had T1DM, each mother described the transition made and the factors that had supported and enabled them to see their situation as *almost ordinary*. Figure 2 presents the key points of this journey from the point of diagnosis (where shock, disbelief, and worry threatened

to overwhelm) to a point of acceptance and patient management of the demands and challenges of caring for a child with T1DM.

Discussion

Participating mothers described initial reactions of shock and disbelief, followed by transition to *near ordinary* or *near normal (85% normal)* family functioning. Family, culture, and faith emerged as critical supports in the whirlwind challenge of balancing multiple demands of a *typical day*, which included the often competing needs of the newly diagnosed child versus the broader family. The emotional distress described by mothers at their child's initial T1DM diagnosis (including feeling overwhelmed, shocked, upset, confused, and overcome with disbelief, worry, and fear) was consistent with that described by parents in Western countries (Bowes et al., 2009; Jönsson, Lundqvist, Tiberg, & Hallström, 2015). In 2005, Welsh researchers described the unexpectedness and rapidity of a T1DM diagnosis as placing parents in a situation they felt ill-equipped to manage (Lowes, Gregory, & Lyne, 2005). Swedish researchers described this time as one of complexity and challenge for the entire family (Jönsson et al., 2015). A study conducted in 2013 reporting on Iranian mothers' experience of diagnosis also spoke of shock, concern, and worry for their child's future, and for one mother, anger at the unfairness of this diagnosis for her young child (Abolhassani et al., 2018).

In this study, mothers feared the impact of T1DM on their child's physical well-being, but also feared the stigmatizing behaviors and attitudes they believed would be directed toward their child as a result of this diagnosis. These mothers had tertiary qualifications in either nursing or pharmacy and could perhaps be expected to be aware of advances in treatment for T1DM and thus more hopeful for their child's future. Nevertheless, worry about adverse judgments, including exclusion from being able to marry, was expressed. Limited understanding of the condition in the broader family and among friends or acquaintances further contributed to the worries these mothers described. These fears were congruent with the recently described experience of stigmatization of children with T1DM and their parents living on the West Bank in Palestine (Elissa, Bratt, Axelsson, Khatib, & Sparud-Lundin, 2017). Palestinian parents reported attempts to conceal the disease and keep it secret, and the children's feelings of being different from others. Similarly, participants in this study feared the impact on their child when others found out about the T1DM diagnosis. Just as the mothers in this study feared for their children's future employment and marriage prospects, mothers in Iran feared that their daughters with T1DM would not be accepted

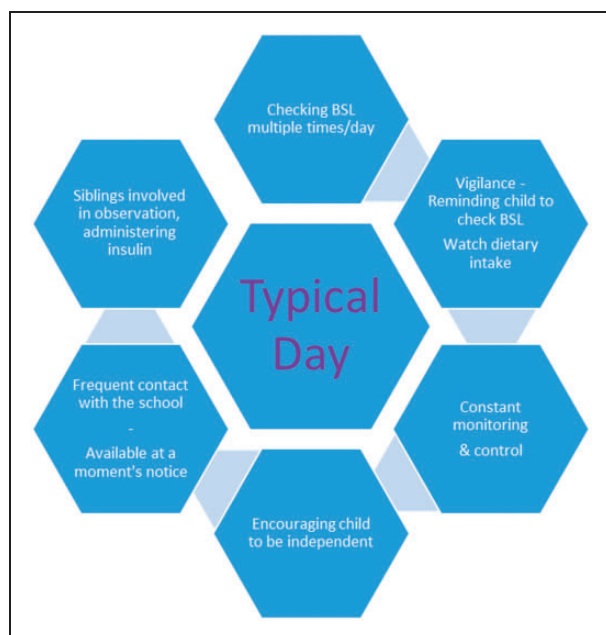


Figure 1. Type 1 diabetes mellitus management tasks in a typical day. BSL = blood sugar level.

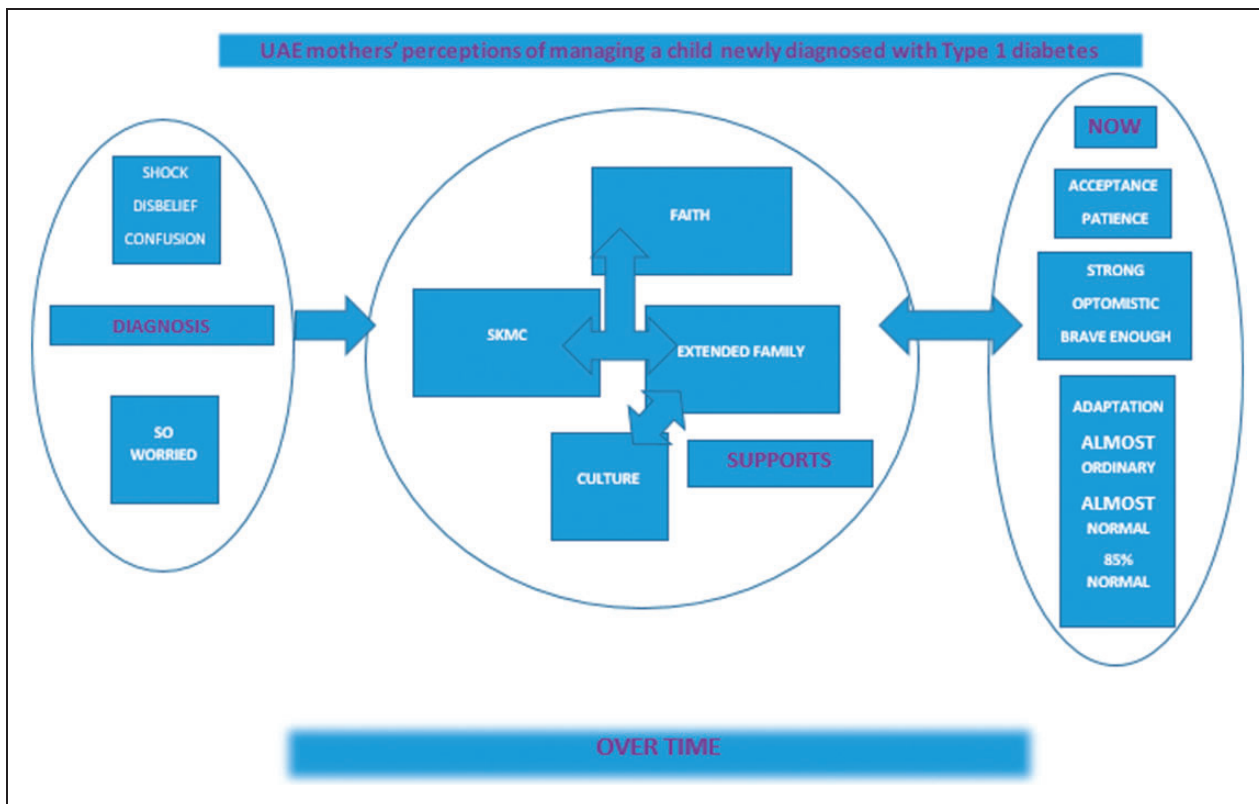


Figure 2. Mothers' responses to their child's diagnosis with type 1 diabetes mellitus. SKMC = Sheikh Khalifa Medical City.

in the community and worried as to whether a man would be interested in marrying a woman with T1DM (Khandan et al., 2018). Experiencing diabetes stigma is not unique to Middle Eastern countries or to mothers parenting a child with T1DM. Recognition of the potential adverse impact of diabetes stigma on self-care and social identity in adults living with T1DM in Australia has recently led to the development of the self-report Type 1 Diabetes Stigma Assessment Scale (Browne, Ventura, Mosely, & Speight, 2017). This scale incorporates three broad areas: treated differently, blame and judgment, and identity concerns. A review of research on stigma directed toward adults with diabetes (both T1DM and Type 2 DM) found a range of specific fears, including being sick, contagiousness, and rejected as a marriage candidate (Abdoli, Doosti Irani, Hardy, & Funnell, 2018). Concerns as to marriageability were noted among young Asian women, with delayed marriage reported in Iran and India (Abdoli et al., 2018), while one "unmarried Arab male in Australia described . . . males and females with diabetes as less desirable candidates for marriage due to a perceived connection between diabetes, erectile dysfunction and the passing of diabetes to their children" (Abouzeid, Philpot, Janus, Coates, & Dunbar, as cited in Abdoli et al., 2018, p. 116). To date, it appears that no studies have focused

on assessing the parameters of diabetes stigma in the T1DM pediatric population or identifying culturally specific beliefs that influence stigma toward children with T1DM and their families.

As mothers in this study sought to adapt and manage their distress, there were supports that provided significant benefit. Each participating mother described support received from extended family including a *listening ear*, moral and material support, encouragement, sympathy, and prayers to Allah on their behalf. The strongly positive role of faith and family permeated the experience of these mothers. Abdel-Khalek (2011) suggested that consistent with other monotheistic religions, Islam includes a range of practices that adherents can use as coping mechanisms when confronted with situations such as that encountered by mothers in this study. Participants specifically mentioned prayers and supplications to Allah made by the mother herself or family members, and faith and acceptance or surrender to the will of Allah. Saudi Arabian researchers recently drew attention to the limited research exploring the role of spiritual coping and religiosity among practicing Muslims experiencing psychological and physical health-related challenges (Cruz et al., 2016). The value that mothers in this study placed on their faith as a coping strategy was consistent with the Saudi study (Cruz et al., 2016) and supports the

recommendation that a focus on spiritual coping be actively incorporated in health-care delivery.

The availability of adequate social support has been linked to improved disease control and decreased stress (Zysberg & Lang, 2015), while the adverse impact of limited psychosocial support on the quality of life reported by maternal caregivers looking after children with T1DM has been reported by Australian researchers (Thorsteinsson et al., 2017). However, mothers in this study identified interactions with extended family and friends as largely positive and an integral component of what helped them to manage and adapt to caring for a child with T1DM. In describing Emirati society, D'raven and Pasha-Zaidi (2016) highlighted a focus on group-based achievements and a concern for "the care, protection and welfare of others." It may be that as members of a collectivist society (Cooper & Brownie, 2018, p. 911), these mothers perhaps had access to a greater level of family support than is generally available to mothers in individualistic societies.

Specific aspects of Islamic culture assisted with coping with the diagnosis of T1DM and managing the disease and also influenced the ways in which families attempted to balance the needs of the child with T1DM and the desire to remain connected and actively participating in cultural events. The importance of fasting during the holy month of Ramadan (as one of the five pillars of Islam) presented specific challenges. The importance of this practice is such that while children and those with chronic diseases are exempt from fasting, many continue to fast. The challenges of managing the Ramadan period of fasting and associated social events where large amounts of sweet foods are served (such as those associated with breaking the fast after dusk each day) have been widely described (Elissa et al., 2017; Peterson, Nayda, & Hill, 2012; Sahay & Nagesh, 2016; Zabeen et al., 2014). In this study, mothers highlighted the importance of inclusion in fasting and breaking their fast with family and friends for the child, so the child did not feel different from the rest of the family.

Each mother spoke strongly of the role that faith, culture, and extended family served in their transition from shock, disbelief, and confusion to now, being able to view themselves as strong, optimistic, and brave enough. The experiences of mothers in this study appear to contradict those reported in other studies, with reference to faith and religion strikingly absent in studies reported in countries such as the United States (Rechenberg et al., 2017), Wales (Bowes et al., 2009), and Australia (Thorsteinsson et al., 2017). Although faith, culture, and extended family were highly valued, these supports were not without challenges that required negotiation and compromise.

A particular challenge for health professionals providing treatment for children with T1DM is

associated with the complexity of the information and skills that are required for effective T1DM management. Rankin et al. (2014) reported parents distressed by information overload and terrified as to how they would manage when they took their child home after the initial diagnosis. Researchers in Scotland emphasized the importance of providing reassurance and attending to the emotional needs of parents of children newly diagnosed with T1DM before providing the complex information associated with T1DM management (Rankin et al., 2014). Of particular note, mothers in the study emphasized the reassurance and sense of hope offered to them; they valued the kindness and gentleness with which they were supported by their health professionals. Contacts with medical and nursing services available to these participants were identified as integral to adjusting to this major change in the child and family's life.

Understanding the experience of parenting a child with T1DM provides insights into the challenges faced by mothers as primary caregivers. All mothers in this study reported feeling satisfied, comfortable, supported, and assisted by the staff with whom they interacted. It is important to note that given their professional training in health care, these mothers may have already been familiar with testing blood sugar levels, administering injections and monitoring a person's health status. Nevertheless, these mothers specifically mentioned practical education (including dietary information), blood glucose monitoring, mothers' support groups, and the positivity and hope expressed by health professionals. The powerful role that the patient-provider relationship plays in increasing patient satisfaction has been well described (Ayala, Howe, Dumser, Buzby, & Murphy, 2014). In addition, attending to parents' personal and emotional needs has been reported to promote parental satisfaction and self-efficacy in caring for a child with T1DM (Kratz, Uding, Trahms, Villareale, & Kieckhefer, 2009). Peer support accessed through attendance at support groups has been identified as a means of reducing mothers' isolation (Smaldone & Ritholz, 2011).

After almost 1 year since the T1DM diagnosis had been made, mothers in this study reported that life was now *near normal*, while also describing the multiple daily demands in caring for a child with T1DM. Swedish researchers explored the experiences of families in which a child had been diagnosed with T1DM 3 years earlier (Wennick, Lundqvist, & Hallström, 2009). Family members spoke of T1DM as being *deeply rooted in their everyday life*, while impacting each person in different ways; parents also felt that the family were more united as a result of the illness (Wennick et al., 2009). The experience of adapting and transitioning to what was now perceived as normal was also described by English researchers who suggested that despite differences in culture, length of time since diagnosis, and

ages, families living with a child with T1DM shared similar experiences (Marshall et al., 2009).

Near normal or *almost normal* was qualified with reference to the impact on relationships and increased anxiety around caring for a child with T1DM. Recent studies have identified significant levels of stress and posttraumatic stress in mothers caring for children with T1DM (Rechenberg et al., 2017). For some mothers, the sense of an impossible task leading to burnout has been described (Lindström, Åman, Norberg, Forssberg, & Anderzén-Carlsson, 2017); for others, worry has been conceptualized as a core aspect of trying to make sure the child is safe (Watt, 2017). The constant management tasks associated with T1DM that mothers in this study described reflected those in other studies, with a typical day including blood glucose monitoring, insulin administration, dietary management, frequent contact with the child's school, vigilance, and needing to be always available (Boogerd et al., 2015; Lindström et al., 2017).

Strengths and Limitations

Each participant had completed qualifications in nursing or pharmacy, and this is a potential limitation of this study. However, educational attainment in GCC countries is high (reported to be higher than countries such as the United States), and these mothers are likely representative of this generation of women in the UAE (Marmenout & Lirio, 2014). Despite high literacy rates, participation in the workforce remains low, thus these participants may have had little experience working as health professionals (Social Vision, 2016). Each of the participants had attended the support group conducted within the hospital, perhaps indicating a proactive approach to seeking support and coping style, and this presents a possible source of bias in the sample. The small number of cases recruited for this study with all participants accessing a single health service limits the generalizability of these findings. However, the in-depth analysis of the data enabled a comprehensive picture of the experience of these Arabic mothers that has not previously been reported and is worthy of consideration for those providing services to mothers of children newly diagnosed with T1DM.

Implications for Practice

The findings from this study underscore the importance of recognizing contextual, cultural, and spiritual factors when caring for families where a child is newly diagnosed with T1DM. Clinicians are encouraged to appreciate the value of including a focus on spiritual coping in health-care delivery. Likewise, the value of emotional support for mothers as caregivers needs to be

an integral component of service provision for families with a child with T1DM. Education programs delivered to schools and community educations that focus to build understanding of T1DM are required to reduce stigmatizing behaviors and attitudes. In settings where child-friendly educational materials are not readily available, the development of such resources needs attention. Given that access to Internet services is readily available across the GCC countries, online support services for children with T1DM and their families require consideration.

Implications for Nursing Research

This study provides an insight into the challenges to be negotiated by a mother caring for a child newly diagnosed with T1DM in the Middle East. The findings suggest multiple areas for further nursing research. These mothers were educated as health professionals and had all participated in a support group conducted at the hospital. To obtain a broader perspective on the experiences of Arabic speaking mothers in the GCC region, replicating this study with a larger group of nonhealth professional mothers who have had no significant contact with T1DM prior to their child being diagnosed with this condition is recommended. Likewise, the authors suggest accessing participants for a further study who have not attended a support group after their child was diagnosed with T1DM.

Mothers in this study were concerned about the potential impact of stigma on their child. Research identifying contextual and cultural beliefs underpinning stigmatizing attitudes and behaviors experienced by children with T1DM and their families in this region is essential to ensure that programs to raise community awareness about T1DM are culturally specific.

The adverse impact on the mental health and well-being of mothers caring for a child with T1DM has been described in studies undertaken in other parts of the world. Although the psychological distress experienced by these mothers is evident in the findings, this study focused primarily on supporting and enabling factors. Information specific to adverse impacts on mental well-being such as a formal diagnosis of depression was not obtained. Further research examining the impact on mental health and psychological well-being of mothers, availability of specialist mental health services, and support and willingness to access such supports would enable further enhancement of health service support.

Conclusion

This study provides insight into the challenges and support needs of mothers who are providing care to a child

newly diagnosed with T1DM in an Arab Muslim context. The impact of a T1DM diagnosis is substantive, with profound psychological and physical demands on mothers and impacts for the broader family. When asked *what helped*, mothers reported faith, culture, extended family, and the presence of competent and empathic health professionals as important support factors. The present findings provide a basis for enhancements in health service support along with themes to inform further research.

Data Accessibility

The deidentified qualitative data used in this study are available from the corresponding author on reasonable request.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Rachel Cathrine Rossiter  <https://orcid.org/0000-0002-6147-861X>

Supplemental material

Supplemental material is available for this article online.

References

- Abdel-Khalek, A. M. (2011). Islam and mental health: A few speculations. *Mental Health, Religion & Culture, 14*(2), 87–92.
- Abdoli, S., Doosti Irani, M., Hardy, L. R., & Funnell, M. (2018). A discussion paper on stigmatizing features of diabetes. *Nursing Open, 5*(2), 113–119. doi:10.1002/nop2.112
- Abolhassani, S., Babaee, S., & Eghbali, M. (2018). Mothers' experience of having children with diabetes. *Iranian Journal of Nursing & Midwifery Research, 18*(4), 304–309.
- Ayala, J., Howe, C., Dumser, S., Buzby, M., & Murphy, K. (2014). Partnerships with providers: Reflections from parents of children with type 1 diabetes. *Western Journal of Nursing Research, 36*(9), 1238–1253.
- Bastawrous, M. (2013). Caregiver burden—A critical discussion. *International Journal of Nursing Studies, 50*(3), 431–441. doi:10.1016/j.ijnurstu.2012.10.005
- Boogerd, E. A., Maas-van Schaaijk, N. M., Noordam, C., Marks, H. J., & Verhaak, C. M. (2015). Parents' experiences, needs, and preferences in pediatric diabetes care: Suggestions for improvement of care and the possible role of the Internet. A qualitative study. *Journal for Specialists in Pediatric Nursing, 20*(3), 218–229.
- Bowes, S., Lowes, L., Warner, J., & Gregory, J. W. (2009). Chronic sorrow in parents of children with type 1 diabetes. *Journal of Advanced Nursing, 65*(5), 992–1000.
- Brinkman, A. K. (2017). Management of type 1 diabetes. *Nursing Clinics of North America, 52*(4), 499–511.
- Browne, J. L., Ventura, A. D., Mosely, K., & Speight, J. (2017). Measuring Type 1 diabetes stigma: Development and validation of the Type 1 Diabetes Stigma Assessment Scale (DSAS-1). *Diabetic Medicine, 34*(12), 1773–1782. doi:10.1111/dme.13507
- Chou, K. R. (2000). Caregiver burden: A concept analysis. *Journal of Pediatric Nursing, 15*(6), 398–407. doi:10.1053/jpdn.2000.16709
- Cooper, J., & Brownie, S. (2018). Perspectives of culture and chronic disease in the United Arab Emirates. In G. Dorman & M. de Chesnay (Eds.), *Case studies in global health policy nursing* (pp. 97–116). New York, NY: Springer Publishing Company.
- Cruz, P., Colet, P. C., Alquwez, N., Inocian, E. P., Al-Otaibi, R. S., & Islam, S. M. (2016). Influence of religiosity and spiritual coping on health-related quality of life in Saudi haemodialysis patients. *Hemodialysis International, 21*(1), 125–132.
- da Cruz, D. S. M., Collet, N., de Anrade, E. M. C., da Nobrega, V. M., & da Nobrega, M. M. L. (2017). Mothers of experiences in diabetic child. *Escola Anna Nery, 21*(1), e20170002.
- D'raven, L., & Pasha-zaidi, N. (2016). Using the PERMA model in the United Arab Emirates. *Social Indicators Research, 125*(3), 905–933.
- Elissa, K., Bratt, E. L., Axelsson, Å. B., Khatib, S., & Sparud-Lundin, C. (2017). Societal norms and conditions and their influence on daily life in children with type 1 diabetes in the West Bank in Palestine. *Journal of Pediatric Nursing, 33*, 16–22.
- Frese, T., & Sandholzer, H. (2013). The epidemiology of type 1 diabetes mellitus. In A. Escher (Ed.), *Type 1 diabetes* (pp. 1–23). London, England: IntechOpen.
- International Diabetes Federation. (2017). *IDF diabetes atlas* (8th ed). Brussels, Belgium: International Diabetes Federation.
- Jönsson, L., Lundqvist, P., Tiberg, I., & Hallström, I. (2015). Type 1 diabetes—Impact on children and parents at diagnosis and 1 year subsequent to the child's diagnosis. *Scandinavian Journal of Caring Science, 29*(1), 126–135.
- Khandan, M., Abazari, F., Targari, B., & Cheraghi, M. A. (2018). Lived experiences of mothers with diabetic children from the transfer of caring role. *International Journal of Community Based Nursing and Midwifery, 6*(1), 76–88.
- Kobos, E., & Imiela, J. (2015). Factors affecting the level of burden of caregivers of children with type 1 diabetes. *Applied Nursing Research, 28*(2), 142–149. doi:10.1016/j.apnr.2014.09.008
- Kratz, L., Uding, N., Trahms, C. M., Villareale, N., & Kieckhefer, G. M. (2009). Managing childhood chronic illness: Parent perspectives and implications for parent-provider relationships. *Family Systems Health, 27*(4), 303–313.

- Lindström, C., Åman, J., Norberg, A. L., Forssberg, M., & Anderzén-Carlsson, A. (2017). "Mission impossible"; the mothering of a child with type 1 diabetes—From the perspective of mothers experiencing burnout. *Journal of Pediatric Nursing, 36*, 149–156.
- Lowes, L., Gregory, J. W., & Lyne, P. (2005). Newly diagnosed childhood diabetes: A psychosocial transition for parents? *Journal of Advanced Nursing, 50*(3), 253–261.
- Maahs, D. M., West, N. A., Lawrence, J. M., & Mayer-Davis, E. J. (2010). Epidemiology of type 1 diabetes. *Endocrinology and Metabolism Clinics of North America, 39*(3), 481–497.
- Macara, C. A., Eaker, E. D., Jannarone, R. J., Davis, D. R., & Stoskopf, C. H. (1993). A measure of perceived burden among caregivers. *Evaluation & the Health Professions, 16*(2), 204–211. doi:10.13072/midss.389
- Marmenout, K., & Lirio, P. (2014). Local female talent retention in the Gulf: Emirati women bending with the wind. *The International Journal of Human Resource Management, 25*(2), 144–166. doi:10.1080/09585192.2013.826916
- Marshall, M., Carter, B., Rose, K., & Brotherton, A. (2009). Living with type 1 diabetes: Perceptions of children and their parents. *Journal of Clinical Nursing, 18*(12), 1703–1710.
- Nurmi, M. A., & Stieber-Roger, K. (2012). Parenting children living with type 1 diabetes: A qualitative study. *Diabetes Education, 38*(4), 530–536.
- Peterson, S., Nayda, R. J., & Hill, P. (2012). Muslim person's experiences of diabetes during Ramadan: Information for health professionals. *Contemporary Nursing, 41*(1), 41–47.
- Rankin, D., Harden, J., Waugh, N., Noyes, K., Barnard, K. D., & Lawton, J. (2014). Parents' information and support needs when their child is diagnosed with type 1 diabetes: A qualitative study. *Health Expectations, 19*(3), 580–591.
- Rearick, E. M., Sullivan-Bolyai, S., Bova, C., & Knafl, K. A. (2011). Parents of children newly diagnosed with type 1 diabetes: Experiences with social support and family management. *Diabetes Education, 37*(4), 508–518.
- Rechenberg, K., Grey, M., & Sadler, L. (2017). Stress and posttraumatic stress in mothers of children with type 1 diabetes. *Journal of Family Nursing, 23*(2), 201–225.
- Sahay, R., & Nagesh, S. (2016). Type 1 diabetes and fasting during Ramzan. *Journal of Social Health and Diabetes, 4*(1), 11–16.
- Sarant, L. (2014). The rising tide of type 1 diabetes. *Nature Middle East*. doi:10.1038/nmiddleeast.2014.266
- Smaldone, A., & Ritholz, M. D. (2011). Perceptions of parenting children with type 1 diabetes diagnosed in early childhood. *Journal of Pediatric Health Care, 25*(2), 87–95.
- Social Vision. (2016). Women in Higher Education in the United Arab Emirates. *Social Vision*. Retrieved from Social Vision: A fusion of values and vision website: <http://www.socialvisiononline.com/articles/content/women-education-united-arab-emirates>.
- Thorsteinnsson, E. B., Loi, N. M., & Rayner, K. (2017). Self-efficacy, relationship satisfaction, and social support: The quality of life of maternal caregivers of children with type 1 diabetes. *PeerJ, 5*, e3961.
- Watt, L. (2017). "Her life rests on your shoulders": Doing worry as emotion work in the care of children with diabetes. *Global Qualitative Nursing Research, 4*, 2333393617743638.
- Wennick, A., & Hallström, I. (2007). Families' lived experience one year after a child was diagnosed with type 1 diabetes. *Journal of Advanced Nursing, 60*(3), 299–307.
- Wennick, A., Lundqvist, A., & Hallström, I. (2009). Everyday experience of families three years after diagnosis of type 1 diabetes in children: A research paper. *Journal of Pediatric Nursing, 24*(3), 222–230.
- Whittemore, R., Jaser, S., Chao, J., Jang, M., & Grey, M. (2012). Psychological experience of parents of children with type 1 diabetes: A systematic mixed-studies review. *Diabetes Education, 38*(4), 562–579.
- Yin, R. K. (2010). *Analyzing qualitative data I: Compiling, disassembling, and reassembling in qualitative research from start to finish* (pp. 176–204). New York, NY: Guilford Publications.
- Zabeen, B., Tayyeb, S., Benarjee, B., Baki, A., Nahar, J., Mohsin, F., . . . , Azad, K. (2014). Fasting during Ramadan in adolescents with diabetes. *Indian Journal of Endocrinology and Metabolism, 18*(1), 44–47.
- Zysberg, L., & Lang, T. (2015). Supporting parents of children with type 1 diabetes mellitus: A literature review. *Patient Intelligence, 7*, 21–31. doi:10.2147/PI.S77566