Journal of Pediatric Nursing 33 (2017) 16-22



Contents lists available at ScienceDirect

Journal of Pediatric Nursing



Societal Norms and Conditions and Their Influence on Daily Life in Children With Type 1 Diabetes in the West Bank in Palestine



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ARTICLE INFO

Article history: Received 12 May 2016 Revised 1 December 2016 Accepted 3 December 2016

Keywords: Type 1 diabetes Qualitative method Child/adolescent Chronic illness Parents

ABSTRACT

Purpose: To explore the experiences of daily life in children with type 1 diabetes (T1D) and their parents living in the West Bank in Palestine.

Design and Methods: A qualitative study using thematic interviews was performed with 10 children with T1D and their parents (n = 10). Content analysis was performed with the assistance of NVIVO 10.

Results: The overall theme was facing the social reality of diabetes. This was underpinned by two themes: stigmatization and social constraints. Facing the social reality of diabetes described children and their parents' everyday life attempts to place themselves within the context of the disease and social context. Children and their parents described how stigmatization and social constraints impacted their daily life as a result of fear of disclosing the disease, which could affect their social status.

Conclusion: These findings highlighted how daily life in children with T1D and their parents was highly affected by cultural impacts, especially as stigma related to the illness affected social interactions of female and male children/adolescents. Lack of knowledge and misunderstandings about T1D in society lead to negative consequences like poorer management of diabetes, and this becomes mediated by gender.

Practical Implications: The findings suggest health care providers need to be aware of the cultural and social impact of T1D on children's and parents' daily life in order to meet their needs and challenges by providing appropriate interventions, strategies and support.

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Background

Living with a chronic condition influences various daily life aspects, including physical, psychological and social dimensions (Mahon, O'Brien, & O'Conor, 2013; Taylor, Gibson, & Franck, 2008). Children and their families' daily lives are significantly affected by chronic diseases (Marshall, Carter, Rose, & Brotherton, 2009). Type 1 diabetes (T1D) is a life-long condition. Living with T1D necessitates that children and their families adhere to rigorous regimen for managing the disease and keeping blood glucose levels within an acceptable range in order to prevent short-term and long-term complications. Managing T1D imposes daily care activities including blood glucose monitoring, physical exercise, regulating dietary intake and frequent insulin injections

(Evert et al., 2008; Nabors & Bartz, 2013; Schmidt, 2007). Adhering to these responsibilities and activities is challenging and creates difficulties against their achievement or maintenance by children and adolescents (Davis et al., 2001; Lehmkuhl et al., 2009; Petitti et al., 2009).

T1D is one of the most frequent and serious chronic childhood diseases (Betts & Swift, 2003; Skrivarhaug, 2013; Soltesz, Patterson, & Dahlquist, 2009; Tolbert, 2009). T1D incidence has increased worldwide (Diamond Project Group, 2006; Harjutsalo, Sund, Knip, & Groop, 2013; Lin et al., 2014). Worldwide, one in every 400-600 children and adolescents are affected by T1D (Evert et al., 2008; Nabors & Bartz, 2013). Approximately, 86,000 children around the world develop T1D each year (International Diabetes Federation, 2015). Since T1D is complex and demanding, (Davis et al., 2001; Marshall et al., 2009; Silverstein & Patrick, 2007) parental support is essential for promoting adherence to diabetes self-care (Miller & Dimatteo, 2013; Nabors, Ritchey, Wassenhove, & Bartz, 2011). Thus, caring for a child with T1D can be emotionally and physically exhausting for parents (Johnson, 2013; Pateraki et al., 2015) and can result in stress and depression, particularly in mothers (Malerbi, Negrato, Gomes, & Brazilian Type 1 Diabetes Study Group, 2012; Nabors et al., 2011; Whittemore, Jaser, Chao, Jang, & Grey, 2012).

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Until recently, most studies of everyday experience in adults, young persons and children with T1D have been conducted in the UK, North America, Sweden and Australia (Fereday, MacDougall, Spizzo, Darbyshire, & Schiller, 2009; Marshall et al., 2009; Smaldone & Ritholz, 2011; Sparud-Lundin et al., 2013; Wennick, Lundqvist, & Hallstrom, 2009). Sociocultural and political context, family dynamics, religion, politics and health care systems vary across societies. Like most traditional societies, Palestinian society is patriarchal. (Haj-Yahia, 2005) and the family is regarded as the main structure of society (Dhami & Sheikh, 2000). The social structure of Arab society is inspired by social values, norms and religion, which are considered to exert their effects on the society's structure and practices.

Living with a chronic illness such as diabetes in occupied territories like the West Bank, Palestine may be associated with challenging social conditions that can impact self-management and societal/family support in daily life. Palestinians' political experiences and living under Israeli occupation have raised fears of losing their cultural belonging and norms. This fear have enhanced the Palestinians struggle to preserve their national identity through strengthening the family ties and adhering to their cultural norms. Further, the sociocultural background influences individuals' beliefs, behaviors, and attitudes toward health and illness (Saca-Hazboun & Glennon, 2011). Hence, there is a need to further explore families' experiences with daily-life management of their children's chronic illness while living under specific social and cultural conditions. With increased knowledge regarding problems in everyday life based on the experiences of those affected, health care professionals are better able to recognize the complexity of living and coping with T1D in these areas and elsewhere with similar conditions. To the author's best of knowledge, there are no studies that investigate children and their experiences with chronic diseases in Palestine. The aim of this study therefore was to explore the experience of daily life in children with T1D and their parents living in the Palestinian West Bank.

Method

Design

The study was conducted using a qualitative descriptive design based on individual interviews, by means of a qualitative content analysis.

Setting

This study was carried out in the West Bank, Palestine. The West Bank has a land area of 5640 km² and an estimated population of 2.65 million (Palestinian Central Bureau of Statistics, 2012). About 73.8% live in urban areas, 16.8% in rural and 9.4% in refugee camps (Palestinian Central Bureau of Statistics, 2012). Palestine is an Arabic state in the Middle East and was occupied by Israel in 1948. The Palestinian Authority (PA) was established on 1994, in accordance with the Oslo Accords peace process. According to these accords, PA was intended to govern parts of the West Bank and Gaza Strip, but with no control over borders, movement of people, goods or control over land and water. Construction of the separation wall, Israeli military closures and their effect on the movement of goods and people restrict Palestinian ability to access to basic services such as health (Giacaman et al., 2009). The majority of Palestinians are Muslim (94%), about 6% are Christian, and only a few are Jewish (Giacaman et al., 2009).

Participants

As part of the recruitment process, letters with study information and consent forms were sent to the Palestine Diabetes Institution and the Diabetes Friends' society that cover cities in the South, North and center of the West Bank asking for their agreement to recruit participants. Upon receiving the agreement of the nurse-in charge at the diabetes clinics and the secretary of the diabetes association, all potential participants were identified and those who met the eligibility criteria and were willing to describe their everyday lives were given the study information letter and consent form. In addition, the participants' contact details were provided by the nurses of the Diabetes clinics and by the secretary of the Diabetes Association. Children who had been diagnosed with T1D at least 6 months prior to the study were eligible for inclusion in the study sample. Children of both sexes aged 8–18 years and their parents agreed to participate. The participants were selected through a purposeful sampling procedure by taking into consideration variety in their residence, age and gender in order to enhance transferability of the results.

Data Collection

Data were collected via face-to-face interviews with ten children (n = 10) with T1D and their parents (n = 10). The interviews were conducted by the first author (KE) and held in the participants' preferred location. Twelve interviews were performed in the participants' homes on their request, while the remaining eight interviews took place in a private room in the diabetes clinic or organization. The children and parents were interviewed individually, which gave them the opportunity to talk openly about their experiences without feeling hampered by each other's presence. Feeling free to describe personal feelings, thoughts and meanings about their daily life with T1D is essential to the activity (Marshall et al., 2009). A thematic interview guide was used and the following main questions were posed: "Can you tell me about your life today compared to before you got your diabetes?", "Can you tell me how you manage your diabetes during an ordinary day at home and school?" and "Can you describe any challenges you face in helping your child manage diabetes?" Follow up questions were used to elicit more detailed information, such as, "What do you mean?", "How do you feel about that?", "Can you give me an example?" All interviews were conducted in Arabic as the participants, the main author (KE) and the fourth author (SK) share this language in common, while the other authors were native Swedish. The interviews, which were audio-taped with the permission of the participants, were conducted between January and August 2014 and lasted between 35 and 70 min. All interviews were transcribed verbatim and translated from Arabic to English by the first author. The translation was a challenge as none of the authors was native English speaker. To maintain the original meaning and to prevent possible translation bias, a person who was fluent in Arabic and English reviewed all transcripts.

Ethical Considerations

Study approval was obtained from the Research Committee at Al-Quds University, Palestine. The participants received written information about the study and before each interview, the parents signed a consent form and the children were also asked if they agreed. Privacy, anonymity and confidentiality were assured. The study was performed according to the Declaration of Helsinki (World Medical Association, 2013).

Data Analysis

The analysis process was performed by using the steps described by Graneheim and Lundman (2004) for qualitative content analysis. The interviews were transcribed verbatim and imported to NVIVO software 10 to facilitate data management and analysis. The transcripts were read a number of times in order to obtain a holistic sense of the participants' experience before being divided into meaning units of words, sentences or paragraphs. These meaning units were then condensed into shorter statements without losing the core meaning. Afterwards, the condensed meaning units were abstracted and labeled with a

Table 1

Example from the analytical process.

Meaning unit	Condensed	Code	Subtheme	Theme	Overall theme
I don't know, I feel it is useless, and every one of my classmates or at school will ask you why and what this means? They are curious and they will keep asking, if one of them knows, the whole school will ask you if it is true that you have diabetes. By time this will be annoying so I don't want to tell them I am a diabetic	Classmates are curious and her diabetes will be Known for everyone in the school if one knows	Wanting to keep her diabetes as private	Keeping illness as a secret	Stigmatization	Facing the social reality of diabetes

code. Finally, through reflective and collaborative discussions among the authors about the accuracy of interpretations throughout the abstraction process, the codes were grouped into themes and subthemes (see Table 1 for example of the analysis process). The transcribed interviews and coding scheme were reviewed by the authors to ensure conformability, trustworthiness and minimize personal bias until consensus was reached.

Results

For information on the demographics of the parents and children, see Table 2. The text analysis revealed one overall theme – Facing the social reality of diabetes – related to two themes and seven subthemes (Fig. 1). The overall theme and subthemes described the children's and parents' everyday life attempts to place themselves within the context of the disease and within the social context. After living with diabetes for a time, many experienced stigmatization and social constraints that could impair their diabetes management due to fear of disclosing diabetes and its effect on social status. In general, the children's and parents' perceptions about diabetes were shaped by societal and traditional gender norms, which affected how they situated the disease into their life. Quotes in this study refer to the participants as father, mother, girl, or boy, followed by age.

Table 2

Socio-demographic data of parents and children.

Variable	Mothers $(n = 6)$	Fathers $(n = 4)$	Children Male $(n = 5)$ Female (n = 5)
Age			
Median (range, min-max)	35.5 (28-49)	37.5 (32-42)	13.5 (8-16)
Standard deviation	7.3	4.1	2.9
Educational level of parents			
High school	4	3	
Diploma			
Bachelor	2	1	
Occupation			
Housewife	6		
Worker		2	
Employee		2	
Residency [*]			
Urban (4000 to 9999 residents)	4	2	6
Rural (<4000 residents)	1	1	2
Camp	1	1	2
Family situation			
Living with two parents	6	4	10
Duration of diabetes			
<1 year	1		3
1–5years	3	2	4
>5 years	2	2	3

* An urban area is an area with population of 10,000 persons or more; A rural area: Any area with population of <4000 persons; Camp: It refers to any locality referred to as a refugee camp and administered by the United Nations Refugees and Work Agency in the Near East.

Stigmatization

Stigmatization represented the experiences of families and children while interacting with their close social network. Children and their parents felt labeled judged and stigmatized by their friends, classmates, relatives and sometimes children perceive themselves as different. This harsh experience left them with deep frustration. It included the following sub-themes: feeling different, concealing signs of the disease, and keeping diabetes a secret.

Feeling Different

Feeling different was one of the main difficulties reported by the interviewed children, as they felt their peers and school perceived them as deviants and some described themselves as different to their classmates. The threat of diabetes complications did not incentivize the children to adhere to their treatment regimens, as for them, maintaining their social image with their peers was more important than controlling their blood sugar. The negative impact of diabetes on their social image affected the children and their interaction with peers, as they felt the latter perceived them as weak and unhealthy. As a result, classmates would sometimes avoid engaging in fights and physical contact with children with diabetes, who, despite their condition, felt normal and wanted to be treated like anyone else in their peer group:

"They think they shouldn't touch me or do anything with me. No one can push me and they say, "You're a diabetes case", so they think if they push me, they will hurt me. This makes me feel like an outsider, but I'm as normal as anyone".

[(Boy, 13.5 years)]

To avoid feeling different, some of the interviewed children and adolescents acknowledged that they never stuck to their diet regimen. Eating like everyone else became a way of acting and being treated the same as any of their "normal" peers.

"I eat everything and I am not on a special diet for diabetes. I usually eat what my mother cooks for all the family. I buy chips or sweets with my pocket money, like other students in school".

[(Girl, 16 years)]

Parents also expressed feelings of stigmatization on behalf of their child and could therefore be sensitive to any reminders about their child's illness and comparisons with other children:

"When people know that she has diabetes, they say 'poor girl' – I hate this word. First, I registered her in a health center next to our house. All the people there were elderly, and they made a big issue of her because they said: "She is still young; may Allah (God) help you".

[(Mother of 8 year-old girl)]

Concealing Signs of the Disease

The children faced several situations that could affect their emotional response and self-care activities. They felt embarrassed when people around them asked questions regarding their diabetes and self-care activities, driving them into more covert behaviors. The children's fear of

Facing the social reality of diabetes				
Stigmatization	Social Constraints			
 Feeling different 	 Restricting social events 			
 Concealing signs of the disease 	 Gender implications 			
 Keeping illness as a secret 	 Excluded from school activities 			
	 Imposing economic burden 			

Fig. 1. Overall theme, themes and subthemes.

being discredited by their peers explained their sensitivity about taking insulin injections or checking blood glucose in front of others. Both the parents and children reported feelings of embarrassment. The children tended to refuse significant self-care activities in order to avoid being rejected or judged by others:

"Now he is 14 years old, he feels shy about taking it in front of us, so he tests his blood sugar and takes the insulin in his room because he considers himself a man now... also he is sensitive, he does not take it in front of the family members, while in the past, he usually did".

[(Father of 14 year-old boy)]

"Socially, I feel my daughter doesn't like to take her injection in front of other people; now she has started asking me to be out of other people's sight in order take the injection".

[(Mother of 8 year-old girl)]

In addition, girls reported different experiences from boys in relation to daily treatment regimens such as taking insulin injections and testing blood sugar. They felt embarrassed when people around them paid attention to their injection marks and this negatively affected their body image. Some of the interviewed girls suffered deeply because these marks served as a constant reminder of their illness. These embarrassing signs of illness intensified their emotional suffering particularly in social interactions:

"The test needle hurts me as it leaves bruises; sometimes people notice the pin holes in my fingers, so I close my hands and sometimes I put them into my T-shirt to cover them or I put my hand in my pocket. The worse thing is when we have parties or ceremonies because I love wearing open things but I can't".

[(Girl, 16 years)]

Keeping illness a Secret

Facing the truth was hard for the children, so for some, concealing their disease from their social network was an individual measure to save face. Most were preoccupied with hiding diabetes management tasks as a way of keeping their illness secret due to fear of rejection and stigmatization if their disease was disclosed. Sometimes they felt pressured by their peers to disclose their illness, although they wanted to keep it private so as not to be the center of attention. They assumed that revealing diabetes could have negative consequences for social interactions, such as being treated or viewed differently by peers and classmates or other people:

"I don't want anyone to know that I have diabetes apart from my close friends and relatives. One of my classmates told me that I'm a diabetic but I denied it. I always think about this subject and how I can manage it... Also, I'm afraid that if my friends' parents know that I have diabetes, they might prevent their children from talking to me, and say I am sick". [(Girl, 14 years)]

Social Constraints

This theme included a variety of aspects, some of which were specific to Arab culture and social norms. Facing the social reality of social constraints is an ongoing process affecting the children with diabetes and their family lifestyle. Social constraints are represented by setting new limits and boundaries for children with diabetes and sometimes for their parents. Social constraints have impact on the children's social network and on their families. It includes the following sub-themes: restricting social events, gender implications, being excluded from school activities, and imposing economic burden.

Restricting Social Events

Some of the mothers spoke about how having a child with diabetes affected their ability to attend social events and made them decline social contact with relatives and neighbors. They also described avoiding social events when their children would refuse to stick to their treatment and decline sweets and unhealthy food that are usually offered at social events as a way of welcoming visitors. Lack of understanding from those around them about encouraging a more appropriate diet not only affected the children, but also their parents, who chose to isolate themselves as a way of physically and socially protecting their children from persistent reminders of their illness:

"I didn't go to many places because she couldn't be with me, and no one else can take care of her but me".

[(Mother of 8 year-old girl)]

"For today, and tomorrow I will not go to social events such as weddings. Even my neighbors are disappointed with me because I don't visit them. Even my mother, I don't visit her, especially when my son doesn't commit to the treatment".

[(Mother of 16 year-old boy)]

The child's diagnosis of T1D changed family life, as diabetes treatment involves adopting a new lifestyle in regard to activities and eating habits to meet the treatment regimen. The children and their parents experienced the loss of their previous social life, as diabetes imposed many restrictions and the need for planning and preparation to meet the increased demands of the condition and treatment goals:

"Before my diagnosis I ate whatever I wanted without worrying, while now I count everything I eat to take insulin instead, also I think a lot about playing; I don't play all the games, I just play specific games". [(Boy, 12 years)]

Gender Implications

Cultural restrictions in Palestine make it difficult for female adolescents to be physically active. Similarly, the female adolescents in this study were described as being prevented from leaving home, being controlled by mothers and fathers and prevented from participating in physical activities outside the home. Conservative social norms and cultural beliefs make it difficult for girls to control their diabetes by being physically active. Physical training is unacceptable in some Palestinian communities and could lead to social implications:

"I like walking, but my mother can't so I can't because girls can't walk alone without a guardian. Also, she prevented me from going out walking with my friends". "As Orientals, our culture and traditions make it difficult for my daughter to walk and run, imagine if she and her sister did that. Everyone would just stare at them and annoy them".

[(Father of 16 year-old girl)]

Excessive and constant surveillance of the girls intensified their suffering, as they were stigmatized not only by their illness but also by their gender. Implication of gender affected different levels of actions and behaviors socially expected by females, thus preventing them from living freely and interacting with others:

"My mother prevented me from going out, and I'm so bored at home. She should trust me more and not be afraid because I'm not a little girl". [(Girl, 14 years)]

The mothers also were deeply saddened by their relatives' indirect accusations of passing the disease to their children. Being blamed for their child's disease led to both internal and external conflicts:

"My relatives pretended that my son had been diabetic since I was pregnant. So, I was sad, that's impossible, how can I bring my boy to life and not discover that he is sick until he is 12?"

[(Mother of 16 year-old boy)]

In regard to girls, the extent of gender implications influenced parents' expectations for their daughters' futures and consequently increased concern about marriage opportunities. The parents' fears about lack of marriage opportunities explained their desire to encourage and empower their daughters to be independent. One obstacle to marriage, as reported by the parents, was that diabetes is a hereditary genetic disease, which could thereby make their daughters seem less attractive as potential wives and mothers. Awareness of this obstacle led to a parent encouraging her daughter to become more independent than her peers:

"I'm worried about her marriage, these feelings and fears, every parent... I'm sure their mind is occupied with, because she has diabetes; although she is still a child, this is her fate, and we depend on God". [(Mother of 8 year-old girl)]

"Her father was so sad, he felt that she will be a burden to him; how will she get married? I don't think she will because she has diabetes. She needs to focus more on her studies and to depend on herself". (Mother of 13.5 year-old girl)

Excluded From School Activities

A lack of understanding about diabetes in the children's close social network, particularly from teachers at school, affected the children emotionally and socially. Some teachers were unable to deal with physical illness and feared complications such as hypoglycemia, which could lead to preventing and excluding boys and girls from participating in different types of activities:

"One day she paid to join the school trip but they gave her the money back and refused to take her because of the big responsibilities... she was so happy to join, then they gave her money back... she cried and cried and was so sad". (Mother of 13.5 year-old girl)

Additionally, playing meant a lot to the children as it included them in a group and was important for building friendship. Depriving children of play and participating in sports or gymnastics was described as hurting them emotionally, as well as socially:

"The teacher stopped me from playing football because he is afraid I will have hypoglycemia or become dizzy, but sometimes he lets me play. Sometimes I don't care, because when I go home I play with my friends; sometimes I cry, because I love sport".

[(Boy, 8 years)]

Imposing Economic Burden

The cost of managing diabetes was an issue for all the parents, as caring for a child with diabetes imposed a large economic burden on them and affected some aspects of life even in families who had medical insurance. Parents were forced to take money from the family's daily allowance to afford treatment:

"Each month, 600 shekels is deducted for my son's treatment, although I have a big family. I always wonder how I will meet their needs. If my son did not have diabetes, I could use this money for my daughter, who is going to university".

[(Father of 8 year-old boy)]

Most parents had governmental medical insurance, but they were forced to buy medical materials because the types of insulin and insulin pens they needed were not available from the Palestinian ministry of health. To afford expensive daily treatment, some parents were forced to borrow from others and to hold more than one job:

"My husband has two jobs: at night he works in the municipality and during the day he works in the ice-cream factory. Sometimes we don't have money, so we have to borrow money from relatives".

[(Mother of 14 year-old girl)]

Discussion

In this study, interviews provided qualitative data regarding experiences of daily life in children with T1D and their parents living in the West Bank in Palestine. The cultural and social contexts in which children with T1D and their parents live have a great impact on their daily life. The lack of knowledge about T1D in society leads to negative consequences, not only for the individual person but also for the whole family. As the parents and children themselves related, they felt stigmatized, believing themselves to be different from their peers because they are sick with an incurable disease. In addition, fears of rejection and labeling by peers and others in their close social network forced them to keep their diabetes a secret. The attitudes and beliefs of society, such as a culture of blaming others for causing the diabetes and feeling fear and disgust toward people with diabetes may play a role in the development of negative stereotyping about people with diabetes (Schabert, Browne, Mosely, & Speight, 2013). The findings of this study are similar to one conducted in the United States in which adolescents with diabetes felt stigmatized and set apart and were angered by their friends' response to their diabetes (Buchbinder et al., 2005). Stigma can have negative outcomes on people with T1D such as impaired psychological well-being, while attempts to conceal the condition may result in avoiding self-care activities (Schabert et al., 2013), with an adverse effect on physical health. Children also have deep frustration and stressors in regard to their feelings of being stigmatized. Given the apparent link between stigma and children's adherence to diabetes management and daily activities, this study found that a sense of being different forced the children to compromise their diabetes self-management in the belief that if they avoided their diabetes regimen, their peers would perceive them as normal and they would fit in with the group. They thus preferred to keep their diabetes a secret in order to be socially accepted and to avoid stigma related to diabetes.

This study provides novel findings about the experience of female adolescents who struggled with their illness and the consequences of traditional gender norms in Arabic society. Parents' concerns about their daughters' future were overwhelming, affecting their plans and hopes of marriage for them. Females with T1D are seen as risking becoming a burden in future marriage as they may not be able to adopt the traditional roles of Arabic women, i.e. caring for children and household responsibilities, due to their condition. Such societal misconceptions imply negative consequences that greatly influence the female adolescent, as well as her parents in the short and long term. In Palestinian society, unmarried women are perceived as failing to assume their traditional role as wife, mother and woman (Haj-Yahia, 2005). In Arabic Muslim families, marriage is a major concern for every man and women and a protection for chastity (Wiktorowicz & Farouki, 2000). In terms of social standing, the well-being of the individual is considered to be highly dependent on a good reputation (Dalky, 2012), which points to a preference for choosing a healthy wife who will fulfill expectations of childbearing without any risks or complications (Goenka, Dobson, Patel, & O'Hare, 2004). In the Middle East, women with diabetes found it difficult to get married, as there is a belief that diabetes can cause infertility among women and Arab society values large families (Khoury, 2001). Moreover, a study conducted in Iran showed that women with T1D are rejected as candidates for marriage (Abdoli, Abazari, & Mardanian, 2013). Similarities between the findings of the Middle Eastern studies and this study are mainly related to socio-cultural and religious (Islamic background) influences. Further, in India, there is also a belief that people with T1D are unable to have healthy, normal children and parents found it difficult to find marriage partners for their diabetic daughters (Kalra, Kalra, & Kumar, 2009; Kanungo, 2015; The Tribune, 2006). Regardless of religion, it is the social values and norms in the Middle East and India which influence females with T1D, as they have to bear the social stigma attached to diabetes and its consequences. These widespread beliefs and misconceptions about T1D can affect the women's social status, although better outcomes have been achieved in recent decades in regard to the health of pregnant women with diabetes and their children due to advances in diabetes care (Kapoor, Sankaran, Hyer, & Shehata, 2007). In contrast, diabetes is considered among the most socially accepted diseases in Western countries, where persons with diabetes do not face the same problems in finding a spouse (Børte & Ottersen, 2012). This could be due to a minimal amount of cultural stigma related to T1D and higher degree of public knowledge about the disease, which in turn may decrease the cultural stigma (Børte & Ottersen, 2012). In addition, some Western countries especially strive to achieve gender equality in regard to the parental role, which may lessen the emphasis on the childbearing role for females with diabetes. However, people from the cultures who stigmatize diabetes who live in Western countries still experience adverse social impacts of diabetes despite living in Western countries because of their culture (Khan, Lasker, & Chowdhury, 2008).

The social constraints on females in Palestinian society involve limiting their mobility, for example, by preventing teenage girls from leaving the house alone to participate in physical sports or even just walking. This finding is not surprising as the context of Palestinian society and its social structure remains male dominated and patriarchal (Haj-Yahia, 2005). In Arab societies, traditional social gender norms determine and shape the roles of both male and female and the context in which they can be physically active (Mabry, Reeves, Eakin, & Owen, 2010). These norms pose a barrier to females with T1D in following recommended lifestyle behaviors and thereby ultimately affect the management of their chronic illness. This could partly explain the inability of several of the interviewed participants to adhere to a diabetes regimen. Likewise, girls in India are culturally bound to remain indoors and avoid participating in outdoor activities and sport alone (Kalra et al., 2009). Our findings also highlight the blaming culture some mothers experienced for giving birth to a child with diabetes. The accusations of close relatives caused them to be concerned not only about their daughters' stigmatization but also about their own reputation. Similarly, another study concluded that a mother is often judged as "good" or "bad", depending on the health outcome and behavior of her children (Tardy, 2000). It is therefore unsurprising to find that families and their children constantly try to keep the chronic disease a secret as their only way to avoid being marginalized and stigmatized. These findings compare well with those of the Indian study, in which parents were found to hide their daughter's diabetes from friends and relatives because T1D is considered a social stigma (Kalra et al., 2009). Similarly, Iranian women with T1D have been shown to live in the shadow and hide their diabetes as a way to avoid being stigmatized (Abdoli, Irani, Parvizi, Fatemi, & Amini, 2013). We can thus summarize by stating that the prerequisites for young people with T1D, especially the female ones, are indeed dependent on where in the world you are born and raised.

The strengths of this study stem from its rigorous qualitative methodology in exploring an area of limited research in the West Bank and the heterogeneity of the families involved. Sampling was based on a purposive selection of participants, which assured that all enrolled had experience of the phenomenon of interest. However, those who did not participate in this study may have had different experiences and perceptions to those who volunteered, a fact that may have implications for potential selection bias.

Moreover, the sample size is relatively small, but in line with qualitative research and conducting in-depth interviews. In addition, the children and their parents were interviewed individually to enable them to talk freely, and this might have contributed to the sharing of stigma experiences. Translation of the interviews from Arabic to English may be a potential limitation in regard to transfer of meaning. To minimize this threat, the first author (KE) translated and interpreted the interview text into English as closely as possible to the original so that the meaning of the participants' experience and the interpretation of the findings were equally close (Van Nes, Abma, Jonsson, & Deeg, 2010).

Conclusion

Cultural factors highly impact on the daily life of children with T1D and their parents, especially as stigma related to the illness affects social interactions in young females and males. Lack of knowledge and misconceptions about T1D in society may lead to negative consequences such as poorer management of diabetes, and this becomes mediated by gender. In particular, the experience of female adolescents and their parents in this study showed that debilitating social and cultural factors continue to discriminate against young females in a way that prevents them from adopting the life style changes needed to stay healthy, but also infringes on their human rights in transition to adulthood.

Implications for Practice

Based on these findings, health care providers working with this group of patients and other significant persons like teachers need to be aware of the stigma attached to diabetes, gender stereotyping and their consequences. This could be achieved by educating the general public about etiology, treatment and facts to decrease misconceptions related to diabetes. Altering societal attitudes and beliefs about T1D is a first step in combating negative consequences associated with diabetes in order to improve adherence to diabetes management. The understanding of cultural and social impact of T1D on daily family life can help health care providers meet the needs and challenges of children, adolescents and their families by providing appropriate interventions, strategies and support.

Conflict of Interest

The authors declare no conflict of interest.

Funding

This research did not received any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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