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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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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'Connor, 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

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