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Health related quality of life and family impact of type 1 diabetes among adolescents in Saudi Arabia

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ABSTRACT

Aim: To measure the health related quality of life (HRQoL) among Saudi Arabian adolescents with type 1 diabetes mellitus (T1DM) and the impact the disease has on the family.

Methodology: A cross sectional study was conducted involving 315 adolescent patients (12–18 years) and their caregivers. Adolescent HRQoL was assessed by adolescents and their parents completing the Peds QL™ Diabetes Module 3.0. Family impact was assessed by the parent completing the Peds QL™ Family Impact module (FIM).

Results: Adolescents reported a cumulative mean HRQoL score of 64.8, while parents reported significantly lower scores of 60.3 ($p = 0.003$). The lowest scores reported by both adolescents and parents were for “Worry”. Female gender and late adolescent age were predictors of lower HRQoL for adolescents with T1DM. The FIM showed low scores for “Emotional functioning” (59.8) and high scores for “Family relationships” (80.9).

Conclusion: These findings emphasize the importance of an interdisciplinary, biopsychosocial and family centered care approach to adolescents with a chronic disease. Future work could assess the effectiveness of direct care involvement of adolescent and mental health experts in improving the HRQoL for this population.

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1. Introduction

Diabetes is a global epidemic with 382 million people affected by the disease worldwide and with figures expected to rise to 582 million by 2035 [1]. In Saudi Arabia, diabetes remains a major public health problem affecting 24% of the population. Furthermore, the burden of type 1 diabetes (T1DM) among children and adolescents in the country has more than

doubled in the past decade with average incidence rates reported at 27.2/100,000 population [2]. T1DM is defined as a metabolic disease characterized by chronic hyperglycemia resulting from absolute insulin deficiency and requiring lifelong insulin replacement therapy [3]. Living with T1DM presents numerous daily challenges associated with disease management to both the adolescent and family and includes such challenges as: intensive therapeutic insulin regimes (daily injections or pump adjustments), need for dietary

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restrictions, regular exercise, and frequent monitoring of biochemical markers [4].

Traditionally, the mainstay of T1DM management has focused on achieving good metabolic (glycemic) control in order to prevent the long-term complications of the disease. Medical practice has shifted, recognizing the importance of treating all dimensions of patient health and not merely the clinical parameters or markers of disease [5]. As such, more attention has been given to assessing and addressing the health related quality of life (HRQoL) of patients. Although there is no universal definition for HRQoL, it broadly describes the impact of an individual's health status on their quality of life in terms of physical, psychological (emotional and cognitive), and social functioning [6]. It has been recommended that part of the process of improving health care includes regularly measuring HRQoL outcomes [7,8]. The HRQoL of children and adolescents with T1DM has been reported by both children and their parents to affect several domains, including school functioning, emotional well-being, and physical and social aspects [9]. Furthermore, HRQoL has been reported to be lower in T1DM children and adolescents compared to healthy counterparts [10]. Adolescents in particular are known to have unique needs based on the significant developmental changes that occur during this transitional period in life [11].

Among patients with T1DM, it has been reported that adolescents have the poorest HRQoL [12–14]. They have been found to have more psychological problems with significant increase risk of depression [8,15,16]. Metabolic control in adolescents with diabetes tends to be poor because of the often challenging necessary lifestyle adjustments required to manage the disease in combination with hormonal and psychosocial changes that occur during this transitional period [17,18]. Knowledge of the HRQoL of adolescents based on the assessment of different domains allows health care providers to tailor their management to meet the individual needs of the adolescent patient [15].

T1DM is often considered to be a disease of the family rather than just the individual affected, due to the integral “role of family relationships and parental support” [19]. Parental reporting of HRQoL is considered important given the young age of patients. Furthermore, studies suggest that taking the parental perspective particularly adds to information gained about the psychological component of HRQoL assessment of youth [20,21]. Studies have reported association between poor adolescent glycemic control with poor adolescent self management which results in high levels of family conflict and distress. Scientific literature reports a negative association between parents who are less responsive toward their adolescent (communication of affection), over reactive in discipline, have low family income and high levels of parental depression with metabolic control and HRQoL for their adolescent with T1DM [19].

Although HRQoL in T1DM adolescents has been looked at in many countries, in Saudi Arabia to date, only one hospital based study has been conducted (reporting HRQoL from the teen's perspective alone) [22]. To gain more information and a better understanding of factors affecting HRQoL for adolescents with T1DM in Saudi Arabia, this study aims to measure the HRQoL of adolescents with T1DM from both the adolescent

and parental perspective. In addition, the impact of the chronic illness on the family will be assessed.

2. Research design and methods

2.1. Study design and settings

This cross-sectional study was carried out during 2012–13 at three of the Ministry of National Guard-Health Affairs (MNGHA) affiliated hospitals in Saudi Arabia following approval by the institutional ethics committee. The MNGHA hospitals are academic hospitals that provide secondary and tertiary care to employees of the National Guard and their dependents. These hospitals also serve as national referral centers for certain chronic disease, including T1DM. The three hospitals are located in Central, Western, and Eastern regions and are among the largest government hospitals in the country.

2.2. Population sample

Participants were recruited from the outpatient clinics at the hospital. Adolescent patients aged 12–18 years and known to have T1DM for at least 1 year were eligible to participate. These subjects along with their parents/caregivers were invited to participate in the study. Participants were recruited by a research assistant who met with the patient and his/her parent/caregiver. A verbal description in addition to written information about the study was provided before written informed consent was obtained to participate in the study.

2.3. Data collection

Demographic and background clinical information on the patient's course of disease, e.g. HbA1C level, method and administrator of insulin delivery, and co morbidities were collected. SES was determined by parental education. Good SES was based on paternal or maternal attainment of post-secondary school education, i.e. completing diploma, university or postgraduate education. Poor SES was based on father or mother completing secondary, intermediate, or primary education or being uneducated. Thereafter, both adolescent and parent/caregiver independently completed the Peds QL™ Diabetes Module ‘teen report’ and ‘parent for teen report’ respectively. Parents/caregivers were also requested to complete the family impact module.

2.3.1. Data collection instruments

Two instruments were adopted and used in this study. The Pediatric Quality of Life Inventory (Peds QL™) Diabetes Module 3.0 and [9] Family Impact module [23] were used with permission. Both instruments underwent forward (into Arabic) and backward translation and were tested prior to their use in this study. The final Arabic versions of the modules can be found online [24].

The first instrument was developed specifically to assess HRQoL for children and adolescents with T1DM. It is multidimensional and contains 5 assessment scales: diabetic symptoms; treatment barriers; treatment adherence; worry; and communication and is measured on a 5-Likert point scale

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