



Diabetes distress in males and females with type 1 diabetes in adolescence and emerging adulthood



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ARTICLE INFO

Article history:

Received 23 February 2016

Received in revised form 12 August 2016

Accepted 14 August 2016

Available online 20 August 2016

Keywords:

Diabetes distress

Type 1 diabetes

Adolescence

Emerging adulthood

Gender-specific differences

ABSTRACT

Background: Age and gender are important factors in the adjustment and psychological well-being of patients with chronic physical illness.

Aim: To explore the gender and age differences in diabetes distress between adolescents and emerging adults with type 1 diabetes (T1D).

Subjects and methods: Diabetes distress was compared in 255 adolescents and 283 emerging adults with T1D using Problem Areas in Diabetes scale.

Results: High diabetes distress level was found in 22.8% of participants.

Lack of confidence in self-care (6.0 vs 3.0, $p = 0.002$), negative emotional consequences (10.0 vs 6.0, $p = 0.004$), and overall score (18.75 vs 11.25, $p = 0.002$) were higher in adult than in adolescent males, when adjusted for age at T1D onset. Negative emotional consequences (13.0 vs 10.0, $p = 0.005$) and overall score (25.0 vs 20.0, $p = 0.016$) were higher in adult compared to adolescent females, when adjusted for age at T1D onset.

Lack of confidence in self-care (6.0 vs 3.0, $p = 0.002$), negative emotional consequences (10.0 vs 6.0, $p = 0.015$), and overall score (20.0 vs 11.2, $p = 0.005$) were higher in adolescent females compared to males, when adjusted for age at T1D onset. Negative emotional consequences score was higher in adult females compared to males (13.0 vs 10.0, $p = 0.029$), when adjusted for age at T1D onset.

In conclusion, our findings show that patients with T1D have greater burden of diabetes distress in emerging adulthood than in adolescence and add to evidence suggesting the importance of addressing diabetes distress in clinical care and the necessity of wider picture beyond the physical manifestation of diabetes to be taken into consideration.

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1. Introduction

Distress in medical patients is often regarded as a normal response to the burden of diagnosis and treatment, discomforting symptoms, and negative social implications. Chronic illness challenges patients' habitual coping strategies, with most eventually reaching good psychological adjustment, but for about 30%, the adjustment phase is longlasting or unsuccessful (de Ridder, Geenen, Kuijer, & van Middendorp, 2008). Patients with type 1 diabetes (T1D) can be seriously burdened by the chronic nature of this disease, which results in diabetes-related emotional distress, impairments of emotional state, and reduced quality of life (Rubin & Peyrot, 1999). The emotional and behavioral challenges generated by diabetes and its management have been labeled "diabetes distress" (Fisher et al., 2015).

Depression and diabetes distress are both prevalent in the individuals with T1D (Northam, Mathews, Anderson, Camerson, & Werther, 2005). Depressive disorder is related to but distinct from diabetes distress. Many patients with high levels of depressive affect are really experiencing diabetes distress, not depression (Fisher et al., 2007). Diabetes distress is defined as an emotional response toward adverse or unpleasant stressors related to diabetes, whereas the definition of depression is based solely on a count of symptoms, irrespective of cause or context (Snoek, Bremmer, & Hermanns, 2015). It was confirmed that diabetes-specific distress is a common condition that often includes high levels of negative affect and is linked to poor behavioral disease management (Fisher, Glasgow, Mullan, Skaff, & Polonsky, 2008).

Age and gender are important factors that moderate the impact of chronic physical illness on patient's adjustment and psychological well-being. In childhood, boys with chronic physical illnesses are more likely than girls to display behavioral and adjustment problems

Conflict of interest: Authors have no conflict of interest.

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(Gortmaker, Walker, Weitzman, & Sobol, 1990). Adolescent girls with T1D are more distressed by their diabetes, experiencing lower self-esteem, more depressive symptoms (Luyckx & Seiffge-Krenke, 2009). Adult males with diabetes are less worried than females about long-term complications and hypoglycaemia but more troubled by the limitation of personal freedom caused by diabetes (Gäfvels, Lithner, & Börjeson, 1993).

Adolescence is a difficult time for patients with T1D. Glycemic control and treatment adherence at the period of adolescence often deteriorate (Mann & Johnston, 1982), and the risk of developing long-term complications seems to accelerate (Schultz et al., 1999). Adolescence is a period in development marked by significant biological, psychological, and social changes (Holmbeck, Friedman, Abad, & Jandasek, 2006). Adolescents face multiple challenges and transitions, including puberty, changes in school, investment in peer and romantic relationships, and shifts in relationships with family (Graber, 2004). Each of these transitions and challenges has the potential to become sources of stress and to increase over the course of the adolescence (Byrne, Davenport, & Mazanov, 2007). In adolescents with T1D, both cross-sectional and longitudinal studies have found a relationship of exposure to stressful life events with diminished glycemic control (Delamater, Kurtz, Bubb, White, & Santiago, 1987; Helgeson, Escobar, Siminerio, & Becker, 2010). Increase in stressful life events is associated with increase in depression, anxiety, low self-esteem, and behavioral problems (Byrne et al., 2007; Johnson et al., 2002), and the presence of depressive symptoms or depression is an amplifier for diabetes-related distress (Hermanns, Kulzer, Krichbaum, Kubiak, & Haak, 2006).

Emerging adulthood is a period of development between the ages of 18 and 25. During this period, youth explore possibilities in the areas of work and love and make choices that will define themselves as adults (Arnett, 2000). The majority of youth graduate from high school and go on to further their education or enter the labor force. From a relationship perspective, emerging adults separate from their families of origin and form attachments to peers, including romantic partners. It is a time of life when different directions remain possible and when the scope of independent exploration of life's possibilities is greater than it will be at any other period of the life course (Arnett, 2000). Emerging adulthood is also the period of development that is associated with the highest rate of risk behaviors (including alcohol and/or drug usage, unprotective sex, driving while intoxicated, and so on) because of the increased freedom at this period of life (Arnett, 2000). There is some evidence that depressive symptoms peak in emerging adulthood (Kessler, Mickelson, Walters, Zhao, & Hamilton, 2004) and reports of stress are higher during this period than any other point in the lifespan (Stone, Schwartz, Broderick, & Deaton, 2010). So, emerging adulthood is a period associated with increased opportunities, as well as increased risk and instability (Arnett, 2007; Luecken & Gress, 2010). The fluctuations that occur in roles, relationships, and living arrangements during emerging adulthood, even if positive, may be stressful. The stress associated with emerging adulthood could be effectively managed by high levels of self-esteem, mastery, and optimism (Helgeson, Reynolds, Siminerio, Becker, & Escobar, 2014). The challenges of emerging adulthood may be even more stressful for those with T1D. Emerging adults with T1D are more likely than those without diabetes to suffer from depressive symptoms (Gendelman et al., 2009). People with T1D, especially females, are at increased risk for eating disorders compared to those without diabetes (Jones, Lawson, Daneman, Olmstead, & Rodin, 2000). Disturbed eating behavior is linked to diabetes-related complications (Rydall, Rodin, Olmsted, Devenyi, & Daneman, 1997). It is possible that, in many adults with T1D diagnosed in childhood, diabetes distress and other psychological problems may develop with the compounded burden of years, or even decades, of disease management (Wolpert & Anderson, 2001).

To date, diabetes distress-related issues are mainly examined in subjects with type 2 diabetes (T2D). Clinical research on diabetes

distress with T2D, however, has not been matched by similar studies with T1D patients, who present with very different disease-related challenges and experiences (Fisher et al., 2015). Data on diabetes distress in T1D and what are diabetes distress possible peculiarities related to gender and age in T1D are very scarce.

The aim of the study was to explore the gender and age differences in diabetes distress between adolescents and emerging adults with type 1 diabetes.

2. Subjects and methods

2.1. Subjects

The cross sectional population-based study was conducted in a single research center as a part of joint Lithuanian–Swiss project “Genetic Diabetes in Lithuania”. Patients who were younger than 25 years old at the time of the project beginning were recruited from the T1D registry in Lithuania. The total Lithuanian–Swiss project “Genetic Diabetes in Lithuania” cohort consisted of 1209 subjects, covering all pediatric patients (<18 years, n = 860) and adult patients between 18 and 25 years old (n = 349) diagnosed with T1D in Lithuania who agreed to participate in the project (70% of all adult patients between 18 and 25 years old agreed to participate).

Of all recruited to the total Lithuanian–Swiss project “Genetic Diabetes in Lithuania” participants, 613 (who at the time of the study beginning were of the age between 14 and 25 years) were asked to fill-in the Problem Areas in Diabetes (PAID) questionnaire. Of them, 538 (87.7%) (258 males and 280 females) agreed, and the data of the filled questionnaires were analyzed in this study. The group of 75 patients who did not agree to fill-in the PAID questionnaire did not differ in terms of T1D duration, age at T1D onset, and HbA1c level.

For the further analysis, study participants were stratified by age: 255 adolescents (123 males and 132 females, age 14 to ≤18 years) and 283 emerging adults (135 males and 148 females, age 18–25 years). Stratification of participants into 2 groups by age was according to Joint WHO/UNICEF Statement that adult person is older than 18 years old (WHO, 1989).

The data on gender, social status (only for adult patients), and insulin delivery method (insulin pumps or multiple daily injections) are presented in Table 1. Of 255 adolescent participants, 84 (32.9%) were using insulin pumps, and 171 (67.1%) were using multiple daily injections (MDI). Of 283 adult participants, 51 (18.1%) were using insulin pumps, and 232 (81.9%) were using MDI. Of 283 adult study participants, 97 (34.3%) had lower than university education, and the rest had graduated university or were still studying there; 116 (40.9%) were employed; 215 (75.9%) were single, 62 (21.9%) were married or cohabiting, and 6 (2.2%) were divorced or separated.

Glycated hemoglobin (HbA1c) level was measured by UniCel DxC 800 Synchron system (Beckman Coulter, USA). The normal cut-off values of HbA1c were 4% to 6% (20–42 mmol/mol).

The study was approved by Lithuanian National Ethical Committee (No. BE-2-5/2013), and written informed consent was obtained from all study participants and their parents or official caregivers. The investigation was carried out in accordance with the Declaration of Helsinki.

2.2. Psychological assessment

Problem Areas in Diabetes (PAID) scale was used for evaluation of diabetes distress of the participants (Polonsky et al., 1995; Welch, Jacobson, & Polonsky, 1997). The PAID comprises 20 items assessing diabetes-related problems. Respondents rate the severity of each problem on a five-point Likert scale (0 – ‘not a problem’ to 4 – ‘serious problem’). Summing all item scores and multiplying by 1.25 results in an overall PAID score, ranging from 0 to 100. Higher scores indicate more severe distress. An overall score equal or higher than 40 was

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