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Diabetes distress in adult type 1 diabetes mellitus men and women with disease onset in childhood and in adulthood

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ABSTRACT

The aim: To determine whether or not diabetes distress varies by age of type 1 diabetes mellitus (T1DM) onset and/or gender.
Subjects and Methods: A total of 700 adult T1DM patients were randomly selected from the Lithuanian Diabetes Registry; 214 of them (30.6%) agreed to participate and were recruited for the study. Diabetes distress (emotional burden, physician-related distress, regimen-related distress, interpersonal distress) was compared in 105 (42 men and 63 women) patients with T1DM diagnosed during 0–18 years of life, and in 109 (61 men and 48 women) with T1DM diagnosed in adulthood, using Diabetes Distress Scale (DDS).
Results: Adult childhood-onset T1DM women have higher regimen-related distress (36.3 ± 21.3 vs 26.6 ± 16.2, $p = 0.016$) than adulthood-onset women.
Adult childhood-onset T1DM women experience higher diabetes distress (higher emotional burden (27.0 ± 22.0 vs 15.6 ± 16.4, $p = 0.006$), physician-related distress (34.4 ± 33.9 vs 20.7 ± 29.4, $p = 0.024$), total diabetes distress (41.2 ± 13.6 vs 34.8 ± 10.9, $p = 0.011$)) than childhood-onset men. Adulthood-onset T1DM women experience higher physician-related distress (39.2 ± 37.6 vs 23.4 ± 32.5, $p = 0.013$), but lower regimen-related distress (26.6 ± 16.2 vs 35.8 ± 21.6, $p = 0.014$) than adulthood-onset men.
In conclusion our findings reinforce the interdependence of psychological and biomedical factors in influencing health outcomes and support the need to provide psychological assessment and support to patients with T1DM.

1. Introduction

Type 1 diabetes mellitus (T1DM) is a life-long and demanding disease with serious health complications. Individuals with T1DM can be seriously burdened by the chronic nature of this disease because of its demand for daily self-management and worries about developing complications, which results in diabetes-related emotional distress, impairments of emotional state and reduced quality of life (Rubin & Peyrot, 1999).

Gender and age of T1DM onset 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 (Gortmaher, Walker, Weitzman, & Sobol, 1990). Adolescent girls with T1DM were found to be more distressed by their diabetes, experiencing lower self-esteem, more depressive symptoms (Luyckx & Seiffge-Krenke, 2009). Adult men with diabetes are less worried than women about long-term complications and hypoglycemia, but more troubled by the limitation of personal freedom caused by diabetes (Gåfvels, Lithner, & Börjeson, 1993).

Patients with childhood-onset T1DM at the period of diagnosis know less about the implication of the disease, and this reduces the intensity of their psychological response to the diagnosis (Gåfvels et al., 1993). Onset of T1DM during the first five years of life may result in better quality of life and less fatalism in the long term. Presumably, these patients have no memory of disease onset, which may reduce trauma and facilitate adaptation to managing life with diabetes (Trento et al., 2014).

Depression and distress are both prevalent in individuals with T1DM (Gendelman et al., 2009; Northam, Mathews, Anderson, Camerson, & Werther, 2005). Researchers have begun to argue, however, that a much larger number of individuals with diabetes experience sub-clinical diabetes-related distress than experience above-threshold psychological disorders, and that this distress may impact glycemic control more than clinical disorders (Esbitt, Tanenbaum, & Gonzalez, 2013; Gonzalez, Fisher, & Polonsky, 2011).

Recent findings have revealed that high levels of diabetes-specific distress, not depression, may account for many of the reported impairments (Hermanns, Kulzer, Krichbaum, Kubiak, & Haak, 2006). Fisher et al. (2007) argue that major depressive disorder is related to but distinct from diabetes distress, and that many patients with high

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levels of depressive affect are really experiencing diabetes distress, not depression. It was confirmed that diabetes-specific distress is a common condition that often includes high levels of negative affect; it is linked to poor biobehavioural disease management, and it can be easily confused with major depressive disorder or minor depression (Fisher, Glasgow, Mullan, Skaff, & Polonsky, 2008). Hermanns et al. (2006) showed that despite some overlap, people with depression and those with diabetes-specific emotional distress did not constitute identical groups in patients with type 1 or type 2 diabetes.

Diabetes distress is a general term that refers to the emotional burdens, stressors and frustrations that stem from managing diabetes (Egede & Dismuke, 2012; Fisher, Hessler, Polonsky, & Mullan, 2012). It is different from the clinical experience of depression (Fisher, Glasgow, & Strycker, 2010a; Nicolucci, et al., 2013). Diabetes distress is defined as patient concerns about disease management, support, emotional burden, and access to care, and is distinctively different from depression, which is not disease-specific or context-specific to diabetes care (Fisher et al., 2007; Polonsky et al., 2005). It was suggested from previous studies that diabetes distress could progress to depression (Fisher, Gonzalez, & Polonsky, 2014; Holt et al., 2014).

Thus, distress is defined as an emotional response toward adverse or unpleasant stressors, whereas the definition of depression is based solely on a count of symptoms, irrespective of cause or context (Snoek, Bremmer, & Hermanns, 2015).

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 long-lasting or unsuccessful (de Ridder, Geenen, Kuijer, & van Middendorp, 2008). Diabetes is associated with an overall risk increase for distress of 30% (Nakaya et al., 2014).

Measures of diabetes distress were found to show moderate to strong positive correlations with self-report measures of depression (Fisher et al., 2010a; van Bastelaar et al., 2010). Moreover, some findings suggest that the presence of depressive symptoms or depression is an amplifier for diabetes-related distress (Hermanns et al., 2006). Regression analyses showed that depression is a predictor for 12-month diabetes distress and vice versa suggesting a bi-directional association (Snoek et al., 2012).

Results from correlational studies showed that depression and diabetes distress are partly overlapping constructs, they are closely related, but not interchangeable concepts (Snoek et al., 2012). Fisher et al. (2014) proposed to consider emotional distress as a core continuous dimension that underlies diabetes-related distress, subclinical depression, elevated depressive symptoms, and major depressive disorder.

It has been shown that depression and diabetes distress are differently associated with diabetes-specific indicators (Fisher et al., 2010b). The results of recent study revealed consistent and significant associations between poorer glycemic control and history of depression diagnosis, depressed mood, and diabetes distress in T2DM patients who initiated insulin therapy (Ascher-Svanum et al., 2015). Fisher et al. (2012) found nonlinear relationship of diabetes-specific emotional distress with HbA1c, diet, self-efficacy, and physical activity with stronger relationships for lower levels of diabetes-specific distress. So, diabetes distress, depression and depressed mood are not only burdensome itself, but also can impede the self-care behaviors of the patients, thereby compromising glycemic control (Metsch, Tillil, Köbberling, & Sartory, 1995).

Some studies suggest that glycemic control is affected more strongly by diabetes distress than by depression, both in type 1 and type 2 diabetes (Fisher et al, 2010a, 2010b; Reddy, Wilhelm, & Campbell, 2013; Strandberg, Graue, Wentzel-Larsen, Peyrot, & Rokne, 2014). Moreover, findings of two independent studies showed that the association between depressive symptoms and glycemic control was explained by diabetes distress (Schmitt et al., 2015; van Bastelaar et al., 2010).

However, diabetes distress related issues are mainly examined in persons with type 2 diabetes. Little is known about diabetes distress in T1DM and what are the differences in diabetes distress of men and women, of childhood-onset and adulthood-onset type 1 diabetic patients.

The aim of the study was to determine whether or not diabetes distress varies by age of T1DM onset and/or gender.

2. Subjects and methods

2.1. Subjects

Kaunas Regional Ethics Committee of Biomedical Researches approved the study (no. BE-2-63/2010). Written informed consent was obtained from all study participants. The investigation was carried out in accordance with the Declaration of Helsinki.

A total of 700 adult T1DM patients, Caucasians by race, were randomly selected from the Lithuanian Diabetes Registry (approximately 7000 adult patients with T1DM); 214 of them (30.6%) agreed to participate and were recruited for the study. Participants were stratified for the period of T1DM onset: 105 childhood-onset (42 men and 63 women) and 109 adulthood-onset (61 men and 48 women).

Stratification of participants into 2 groups for the period of T1DM onset was according to a joint WHO/UNICEF Statement that child is 0–18 years old and adult person is older than 18 years old (WHO, United Nations Population Fund, & UNICEF, 1989).

The mean age of all participants was 33.8 ± 12.0 years. Data on sex, age, age of diabetes onset of adult participants of the study with childhood- and adulthood-onset type 1 diabetes mellitus are presented in Table 1. The mean T1DM duration is similar between childhood and adulthood onset groups. This means that most of the childhood-onset patients were adolescents at diagnosis and the adult sample were mainly young adults.

No diabetic complications were found in 60 participants of the study (30.0%; 95% CI 23.3–38.6), one complication (retinopathy, nephropathy or neuropathy) in 45 (22.5%; 95% CI 16.8–30.1), two complications in 51 (25.5%; 95% CI 19.4–33.6), three complications in 44 (22.0%; 95% CI 26.4–29.6) patients. Retinopathy was found in 108 participants (54.0%; 95% CI 44.7–65.2), nephropathy in 49 (24.5%; 95% CI 18.5–32.4), neuropathy in 122 (61.0%; 95% CI 51.1–72.8).

Antidepressant medicaments were used by 10 (5.0%; 95% CI 2.7–9.3) participants and antipsychotic medicaments under psychiatric prescription were used by 4 (2.0%; 95% CI 0.7–5.3).

Of all study participants, 125 (58.4%; 95% CI 55.1–78.2) had lower than university education, and all other had graduated university or were still studying there.

Measurement of glycosylated hemoglobin (HbA1c) in venous blood was performed by analyzer "Dimension Clinical Chemistry System" (DCA2000 +, Bayer Inc., USA).

2.2. Psychological assessment

Diabetes Distress Scale (DDS) was used for evaluation of diabetes distress of the participants (Fisher et al., 2008; Polonsky et al., 2005).

Table 1
Characteristics of the study participants.

Categories	Gender	T1DM onset in:		p-value
		Childhood	Adulthood	
Participants of the study, n (%)	Men	42 (48.8)	61 (59.2)	0.019
	Women	63 (56.8)	48 (43.2)	
	Total	105 (48.6)	109 (51.4)	
Age, years (mean ± SD)	Men	25.9 ± 8.1	41.0 ± 9.2	<0.001
	Women	26.3 ± 7.7	40.3 ± 10.9	<0.001
	Total	26.1 ± 7.9	40.7 ± 9.9	<0.001
Age at T1DM onset, years (mean ± SD)	Men	11.6 ± 4.9	27.7 ± 5.6	<0.001
	Women	10.7 ± 3.9	26.3 ± 5.8	<0.001
	Total	11.0 ± 4.3	27.1 ± 5.7	<0.001

SD – standard deviation.