Diabetes distress from the patient's perspective: Qualitative themes and treatment regimen differences among adults with type 2 diabetes,

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ABSTRACT

Aims: To explore diabetes distress in a sample of adults with type 2 diabetes, treated and not treated with insulin.
Methods: Six focus groups were conducted with 32 adults with type 2 diabetes, divided by treatment regimen (insulin-treated $N = 15$; 67% female; 60% black; 46% Hispanic; M age 54; M HbA1c 73 mmol/mol (8.8%); non-insulin-treated $N = 17$; 53% female; 65% black; 13% Hispanic; M age 58; M HbA1c 55 mmol/mol (7.2%)). A coding team transcribed and analyzed interviews to describe themes. Themes were then compared between groups and with existing diabetes distress measures.
Results: Participants in both groups described a range of sources of diabetes distress, including lack of support/ understanding from others, difficulties communicating with providers, and distress from the burden of lifestyle changes. Insulin-treated participants described significant emotional distress related to the burden of their insulin regimen. They were more likely to report physical burden related to diabetes; to describe feeling depressed as a result of diabetes; and to express distress related to challenges with glycemic control. Non-insulin-treated participants were more likely to discuss the burden of comorbid medical illnesses.
Conclusions: Our data generate hypotheses for further study into the emotional burdens of diabetes for insulin-treated adults with type 2 diabetes and are in line with quantitative research documenting increased diabetes-related distress among insulin-treated individuals. Data describe needs, currently unmet by most models of care, for comprehensive assessment and tailored management of diabetes-related distress.

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1. Introduction

Diabetes-related distress – emotional distress related to the burdens of living with diabetes and its management – is common among adults with type 2 diabetes mellitus (Type 2 DM) (Snoek, Bremmer, & Hermanns, 2015). Diabetes distress encompasses burdens of the intensive self-management regimen, emotional distress, worries about glycemic control, and distress or frustration over not receiving sufficient support from loved ones and providers for managing diabetes (Polonsky et al., 1995). A growing body of literature has differentiated diabetes distress from clinical depression,

suggesting that diabetes distress is more closely linked to worse illness self-management and treatment outcomes (Fisher et al., 2007; Fisher et al., 2008; Fisher et al., 2010) and supporting the development of promising interventions for diabetes distress (Hessler et al., 2014; Fisher et al., 2013). This empirical evidence is complemented by in-depth qualitative studies in diabetes that consistently suggest that clinical depression is too narrow of a construct to capture the diverse emotional experiences described by distressed patients (Gask, Macdonald, & Bower, 2011).

While regimen-related distress is an important aspect of diabetes distress in adults with type 2 diabetes, as measured by existing self-report scales, e.g., Problem Areas in Diabetes (PAID) (Polonsky et al., 1995), Diabetes Distress Scale (DDS) (Polonsky et al., 2005a), few studies have provided for an in-depth exploration of the relationship between the diabetes treatment regimen and the experience of emotional distress. For adults with Type 2 DM, insulin initiation is typically recommended when patients are not meeting glycemic goals with oral medications and lifestyle changes alone (Nathan et al., 2006; Holman et al., 2007); about 22% of adults with Type 2 DM over the age of 40 are prescribed insulin (Li et al., 2012). Type 2 diabetes patients often hold negative attitudes about insulin

therapy and are reluctant to begin insulin when indicated (Polonsky, Fisher, Guzman, Villa-Caballero, & Edelman, 2005b). Negative attitudes and concerns about potential harms from insulin therapy, including belief in myths that insulin causes complications like blindness, are particularly common among ethnic minorities and those with lower socioeconomic status (Polonsky, Fisher, et al., 2005b; Caballero et al., 2004). Once prescribed, adherence to insulin therapy also appears to be lower than for oral medications among adults with Type 2 DM (Cramer, 2004). Thus, better understanding the distressing aspects of managing diabetes among those treated with insulin may improve the refinement of tailored interventions for diabetes distress and self-management.

Previous quantitative research has suggested that adults with Type 2 DM treated with insulin therapy report significantly more diabetes distress, particularly regimen-related distress, compared to those not prescribed insulin (Delahanty et al., 2007; Baek, Tanenbaum, & Gonzalez, 2014). A large, population-based U.S. survey found that adults with Type 2 DM treated with insulin had higher rates of major depression than adults with Type 2 DM not prescribed insulin (Li, Ford, Strine, & Mokdad, 2008). Delahanty and colleagues (Delahanty et al., 2007) found that increased diabetes distress in adults with insulin-treated Type 2 DM was primarily explained by increased illness severity, as well as the burden of insulin treatment. In a previous empirical study of adults with Type 2 DM, we observed higher levels of diabetes emotional burden and regimen-related distress in insulin-treated patients and found that, independent of complications and other covariates, insulin treatment was associated with higher levels of diabetes distress among patients with low levels of social support (Baek et al., 2014). These findings suggest that insulin-treated adults with Type 2 DM are at increased risk for diabetes distress, partly through increased disease burden and possibly due to increased burden of self-management.

The aim of the current study was to use qualitative methods to provide an in-depth exploration of patients' experience with each of these sources of distress, using focus groups with a diverse sample of adults treated for Type 2 DM, grouped by their treatment regimen (oral medications only vs. regimens that included insulin). The goals of the study were to elicit descriptions of diabetes distress from the perspectives of adults with Type 2 DM and to code and compare the themes represented in these descriptions to explore similarities and differences between the treatment regimen groups.

2. Methods

2.1. Recruitment

Eligible participants were English-speaking adults (over 18) with a self-reported diagnosis of Type 2 DM for a minimum of one year, who were being treated with oral medication for diabetes, and had participated in a larger quantitative study on diabetes self-management and emotional distress. Participants with significant cognitive impairments that could interfere with completing the larger study were ineligible, as were participants with active suicidality. Participants were recruited for the larger study through mailings, direct referrals, clinic screenings, and flyers at the Montefiore Clinical Diabetes Program and affiliated primary care clinics in the Bronx, NY, serving a predominately urban, ethnic minority population. Those who completed the study received a follow-up call inquiring about participation in a focus group. Quantitative data collected from the larger study included HbA1c via blood draw, and self-reported demographics, number of prescribed medications, years since diagnosis, a self-report battery assessing diabetes distress and other psychosocial issues. The Institutional Review Board at the Albert Einstein College of Medicine approved study procedures. Participants provided informed consent.

2.2. Study visit

Participants attended focus groups, conducted by advanced clinical psychology graduate students trained in qualitative research methods. A focus group format was used because groups have the potential to elicit rich data about common experiences between members, which may be less likely to arise through individual interviews (Rabiee, 2004). Two facilitators co-led each group. An interview guide (Table 1) promoted consistency across groups and between facilitators. Groups were divided by treatment regimen (3 insulin-treated, 3 non-insulin-treated groups); each group had between 3 and 7 members. Groups lasted between 90 and 120 minutes and were audiotaped and transcribed. Participants were compensated $25. Recruitment stopped when no new themes arose and theoretical saturation was reached; this occurred with the 5th and 6th groups.

2.3. Measures

Participants provided demographic and health information, including length of time since diagnosis, number of medications, and number of diabetes-related complications. They completed the Charlson comorbidity index which includes 22 yes/no medical history questions that cover cardiac, vascular, neurologic, and other medical comorbidities (Charlson, Pompei, Ales, & MacKenzie, 1987). They also completed the Diabetes Distress Scale (DDS), a 17-item measure assessing the experience of distress associated with diabetes over the past month across four domains: emotional burden, physician-related distress, regimen-related distress, and interpersonal distress (Polonsky, Fisher, et al., 2005a). Clinically meaningful cut-points have been established in adults with Type 2 DM, with a mean score greater than 2.0 indicating moderate distress and scores greater than or equal to 3.0 indicating high distress (Fisher, Hessler, Polonsky, & Mullan, 2012). The total DDS score had excellent internal reliability in this sample (Cronbach's alpha = .95).

2.4. Data analysis

Qualitative data were analyzed using thematic analysis (Braun & Clarke, 2006). In the first open-coding phase, three coders (clinical psychology graduate students with qualitative research training) independently read one transcript and highlighted relevant text. The coders then met to create an initial codebook for use as a flexible guide for coding remaining transcripts. The coding team was expanded to include 12 members of our research lab (all clinical health psychology graduate students and a clinical health psychologist). The use of a coding team enabled investigator triangulation to support credibility of the data (Patton, 1999). Members all received coding training. Two to three coders were assigned to each transcript. Each group followed the same process of coding independently, generated additional codes when needed, and met

Table 1
Focus group questions.

1. What has been hard for you about having diabetes? What have you struggled with?
   Areas to probe:
   - Medical/self-management (e.g., glucose self-monitoring, taking medications and insulin)
   - Emotional/personal
   - Social (family; fear of poor outcomes based on experience of other people with diabetes)
2. Many people with diabetes find that their emotions affect their diabetes. Do you think your diabetes and emotions are related? How?
   Areas to probe:
   - Positive emotions? Negative emotions?
   - Do emotions affect diabetes and self-management? If yes, how?
   - Does diabetes affect your mood? If yes, how?
   - Support for emotional aspects of diabetes? From friends, family, health care providers?