



## Understanding the sources of diabetes distress in adults with type 1 diabetes



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### ABSTRACT

**Aims:** To identify the unique sources of diabetes distress (DD) for adults with type 1 diabetes (T1D).

**Methods:** Sources of DD were developed from qualitative interviews with 25 T1D adults and 10 diabetes health care providers. Survey items were then developed and analyzed using both exploratory (EFA) and confirmatory (CFA) analyses on two patient samples. Construct validity was assessed by correlations with depressive symptoms (PHQ8), complications, HbA1C, BMI, and hypoglycemia worry scale (HWS). Scale cut-points were created using multiple regression.

**Results:** An EFA with 305 U.S. participants yielded 7 coherent, reliable sources of distress that were replicated by a CFA with 109 Canadian participants: Powerlessness, Negative Social Perceptions, Physician Distress, Friend/Family Distress, Hypoglycemia Distress, Management Distress, Eating Distress. Prevalence of DD was high with 41.6% reporting at least moderate DD. Higher DD was reported for women, those with complications, poor glycemic control, younger age, without a partner, and non-White patients.

**Conclusions:** We identified a profile of seven major sources of DD among T1D using a newly developed assessment instrument. The prevalence of DD is high and is related to glycemic control and several patient demographic and disease-related patient characteristics, arguing for a need to address DD in clinical care.

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### 1. Introduction

The successful management of diabetes requires ongoing attention to a complex and demanding set of self-care tasks. Many individuals with diabetes report frustration with the burdens of disease management and they experience worries, fears, and concerns about the potential emergence of complications, erratic blood glucose

numbers, hypoglycemic episodes, and feelings of “diabetes burnout” (Polonsky, 1999). Taken together, the emotional and behavioral challenges generated by diabetes and its management have been labeled “diabetes distress” (DD), which has been found to be distinct from clinical depression and, unlike depression, has been directly linked to poor glycemic control and problematic self-care behaviors (Delahanty et al., 2007; Fisher et al., 2013; Hessler et al., 2014; Lloyd, Smith, & K, 2005; Ogbera & Adeyemi-Doro, 2011).

To date, most studies have examined DD among adults with type 2 diabetes (T2D) (Dunn, Smartt, Beeney, & Turtle, 1986; Herschbach et al., 1997; Polonsky et al., 1995). These studies have led to the identification of common sources of diabetes-related distress in this population and the development and validation of measures that can be used in research and clinical care to identify both the level and key sources of distress during clinical visits (Polonsky et al., 2005). Clinical research on DD with T2D adults, however, has not been matched by similar studies with T1D adults, who present with very different disease-related challenges and experiences. For example, a recent qualitative study reported that DD was common among T1D patients

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and identified several sources likely to be unique to T1D, including a sense of self-consciousness about T1D, concern about being misidentified as having T2D, day-to-day management distress, healthcare system struggles, fears about complications and the future, and concerns about pregnancy (Balfe et al., 2013). Unfortunately, many measures of DD developed for use with T2D adults do not include commonly expressed concerns of T1D patients, e.g., pronounced fear of hypoglycemia, feelings of powerlessness, a sense of burnout due to the pervasive and unremitting disease management demands. Last, among T1D adults there has been as yet no systematic exploration of the relationship of DD to a variety of patient disease-related and demographic characteristics. Such information can be helpful in identifying T1D populations at particular risk for DD so that preventative interventions can take place.

To address these gaps, the goals of this study were to: identify the unique content, sources and prevalence of DD among adults with T1D; document the relative levels of severity of different sources of DD; determine how patient demographic and disease-related characteristics are associated with DD to help identify T1D patients at risk; and to apply these findings to clinical care by developing a reliable and valid assessment device that can be used to assess DD in adult T1D patients.

## 2. Methods

To systematically identify the primary sources of DD among adults with T1D, we used a literature review to reveal common themes plus a one-hour, qualitative, structured interview conducted with 25 adults with T1D (age  $\geq 19$ ), stratified by age, gender, and years with T1D. Similar interviews were conducted with 10 diabetes health care providers (MDs, CDEs, dietitians). Interviewees were asked: “What about T1D drives you crazy?” and “What particular aspects of diabetes are the most difficult for you?” Respondent descriptions of the distress-related aspects of diabetes and its management were reviewed for duplication and converted into 59 survey items. Participants and providers then reviewed the items for clarity. A 6-point response scale was used to rate each item: 1 = “not a problem” to 6 = “a very serious problem”. The items were part of an online assessment battery that documented participant demographics, diabetes status, and current diabetes management. It also included previously validated instruments to be used for verifying the construct validity of the survey.

A new sample of adults with type 1 diabetes was then recruited from several academic and community diabetes clinics in California and Ontario, Canada to assure diverse samples. Using the same inclusion criteria, clinic staff identified all eligible individuals during regular visits or sent letters to all eligible individuals informing them that they would receive a telephone call from a project representative if they did not opt out by either calling a toll-free number or returning an enclosed postcard. All participants were screened for eligibility by telephone, and, if interested, were emailed a confidential, HIPAA-protected personal link to the online survey, which included an informed consent form. Participants also provided permission for their health care provider to release their most recent HbA1C results. Participants received a \$15 electronic gift card for participation. Nine months after initial assessment, a new survey was sent to the 289 U.S. patients who agreed to allow us to contact them to complete an additional survey to assess survey test–retest reliability. The study received approval from the UCSF Committee on Human Research and data were collected in 2013–2014.

### 2.1. Measures

Demographic measures included age, gender, ethnicity (White/non-White), education (years), living with a partner, and age at diagnosis. Diabetes status included the latest clinic-recorded HbA1C within six months, body mass index (BMI; self-reported weight and

height), current form of insulin delivery (pump vs. multiple daily injections), current use of real-time continuous glucose monitor (CGM), and number of diabetes complications from a list of 8.

Three scales were included to assess the construct validity of the survey, called the T1-Diabetes Distress Scale (T1-DDS). The Patient Health Questionnaire-8 (PHQ-8) (Kroenke, Spitzer, & Williams, 2001) contains 8 items that assess depressive symptoms linked to DSM-V criteria for Major Depressive Disorder (alpha = .89). The suicide item was omitted. The World Health Organization-5 (WHO-5) is a 5-item scale that assesses quality of life (Hajos et al., 2013) (alpha = .86). The 18-item Worry subscale of the Hypoglycemia Fear Survey-II (HFS-W) assesses worries and concerns specifically related to hypoglycemia (Gonder-Frederick et al., 2011) (alpha = .94).

### 2.2. Data analysis

Following completion of the qualitative interview that yielded 59 survey items, exploratory principal components factor analyses (EFAs) using both orthogonal (Varimax) and oblique (Promax) rotations were specified with the U.S. data and conducted with SPSS software (PASW Statistics, v. 19). Once a final factor solution was accepted with the U.S. data, a confirmatory factor analysis (CFA) was undertaken with both the U.S. and Canadian samples, using Mplus software (v. 6.11) (Muthen & Muthen, 2012).

DD subscales were created from the two datasets by averaging across items in each factor. Internal consistency of subscales was determined by Cronbach’s alpha (Cronbach (1951)) and 9-month test–retest reliability was determined by Pearson correlation. To determine construct validity, Pearson correlation coefficients were generated between the T1-DDS scales and the PHQ-8, number of complications, WHO-5, HbA1C, BMI, and HFS-W measures.

To establish scale cut points, a three-step multiple-regression analysis was performed (Fisher, Hessler, Polonsky, & Mullan, 2012), examining linear and quadratic relationships between the total distress score and HbA1C. HbA1C was considered the exclusive dependent variable because of its general importance in clinical settings. Age, gender, education, diabetes duration, ethnicity, pump vs. non-pump status, and BMI were entered in the first step, a linear T1-DDS term was entered in the second step, and a quadratic (curvilinear) T1-DDS term was entered in the third step. Patient characteristics associated with DD were assessed by *t*-test and chi square.

## 3. Results

Of 348 eligible U.S. individuals (the exploratory sample), 305 completed the online survey (87.0%). Expressions of interest were received from 117 eligible Canadian individuals (the confirmatory sample) and 109 completed the survey (93.2%) (Table 1). The Canadian sample, in contrast to the U.S. sample, reported a significantly longer duration of diabetes, had less academic education, a greater frequency of married individuals, higher HbA1C and BMI, and more long-term complications. These differences were expected, as the goal was to include diverse samples to maximize the generalizability of the findings. Of the 305 U.S. patients who completed the initial survey, 289 agreed to allow us to contact them 9 months later to complete a second survey for test–retest analyses (94%). Of these, 224 completed the second survey (77.5%). There were no significant differences between the original U.S. sample and those who completed the second survey at 9 months on any demographic or diabetes status variable.

### 3.1. Sources of DD in adults with T1D

A detailed analysis of the original 59 scale items was undertaken to identify sources of DD in this patient population. Of the original items, 9 were dropped due to non-normal item distributions or correlations of  $\geq .70$  with other items. The EFA with the U.S. sample yielded a

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