HHS Public Access

Author manuscript

J Diabetes Complications. Author manuscript; available in PMC 2016 May 01.

Published in final edited form as:

J Diabetes Complications. 2015 ; 29(4): 572–577. doi:10.1016/j.jdiacomp.2015.01.012.

UNDERSTANDING THE SOURCES OF DIABETES DISTRESS IN ADULTS WITH TYPE 1 DIABETES

Lawrence Fisher[1], **William H. Polonsky**[2], **Danielle M. Hessler**[1], **Umesh Masharani**[3], **Ian Blumer**[4], **Anne L. Peters**[5], **Lisa A. Strycker**[6], and **Vicky Bowyer**[1]

[1]Department of Family & Community Medicine, UCSF, San Francisco, California

[2]Behavioral Diabetes Institute, San Diego, California

[3]Department of Medicine, UCSF, San Francisco, California

[4]Charles H. Best Diabetes Centre, Ontario, Canada

[5]University of Southern California, Los Angeles, California

[6]Oregon Research Institute, Eugene, Oregon

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.

Corresponding Author: Lawrence Fisher, Ph.D., ABPP, Box 0900, Department of Family & Community Medicine, UCSF, San Francisco, CA 94143, 415-476-5403, Fax 415-476-6051, fisherl@fcm.ucsf.edu.

Conflicts of interest:

Lawrence Fisher: Consultant to Roche Diagnostics, Elli Lilly.

Ian Blumer: Consultant to or advisory board with to Animas, Bayer, BD Diabetes, BMS/AZ, Elli Lilly, Janssen, Medtronic, Merck, Novo Nordisk, Roche, Sanofi.

William Polonsky: Consultant or advisory board with Sanofi, Novo Nordisk, Elli Lilly, Dexcom, Abbott, J&J, Boehringer Ingelheim, Takeda, Roche.

Anne Peters: Consultant or advisory board with Amgen, Abbott Diabetes Care, Becton Dickinson, Biodel, Bristol Myers Squibb/ Astra-Zeneca, Janssen, Lexicon, Lilly, Medtronic Minimed, Novo Nordisk, OptumRx, sanofi, Takeda, Thermalin. Speakers bureau = Bristol Myers Squibb/Astra-Zeneca, Novo Nordisk, Janssen.

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.

Keywords

diabetes distress; type 1 diabetes; distress profile; assessing distress; types of distress

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; D. H. 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 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 common 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 ≥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 (EFA) 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 ≥ .70 with other items. The EFA with the U.S. sample yielded a 7-factor solution (eigenvalues ≥ 1.00), accounting for 67.2% of the common item variance, after cross- and poorly loaded items were eliminated. Results were similar with both Varimax and Promax. Additional EFAs then were conducted to force 4-, 5-, 6-, 8-, and 9-factor solutions to determine whether a more parsimonious factor structure might emerge or whether meaningful new factors that identified new sources of DD might be generated beyond the original 7. These additional EFAs did not add any meaningful new factors. Consequently, the 7-factor, 28-item solution was accepted. The underlying factor structure was similar in analyses conducted for separate gender and age groups (median split). Factor loadings are presented in Table 2.

A CFA of the 7-factor solution to confirm sources of DD was undertaken with the Canadian sample, and a similar CFA model was specified with the U.S. sample for comparison. In both CFA models, all 28 items significantly loaded on the same 7 factors derived from the EFA (all $p \leq .001$), providing support for the viability of the 7-factor solution. The overall model fit of the U.S. CFA model was: $\chi^2(df) = 778.253(329)$, $p < .001$; Comparative Fit Index = .89; Root Mean Square Error of Approximation [90% CI] = .07 [.06 .07], Standardized Root Mean Square Residual = .06. The fit to the Canadian data was somewhat only modest: $\chi^2(df) = 713.412(329)$, $p < .001$; CFI = .79; RMSEA [90% CI] = .10 [.09 .11]; SRMR = .10. Considering the dissimilarity of the U.S. and Canadian samples, the CFA results supported the viability of the 7-factor solution.

The final subscales that reflected different sources of DD (Table 2), with many reflecting areas that are unique to T1D patients, were: *Powerlessness* (a broad sense of feeling discouraged about diabetes; e.g., “feeling that no matter how hard I try with my diabetes, it will never be good enough”), *Negative Social Perceptions* (concerns about the possible negative judgments of others; e.g., “I have to hide my diabetes from other people”), *Physician Distress* (disappointment with current health care professionals; e.g., “feeling that I don’t get help I really need from my diabetes doctor”), *Friend/Family Distress* (there is too much focus on diabetes amongst loved ones; e.g., “my family and friends make a bigger deal out of diabetes than they should”), *Hypoglycemia Distress* (concerns about severe hypoglycemic events; e.g., “I can’t ever be safe from the possibility of a serious hypoglycemic event”), *Management Distress* (disappointment with one’s own self-care efforts; e.g., “I don’t give my diabetes as much attention as I probably should”), and *Eating Distress* (concerns that one’s eating is out of control; e.g., “thoughts about food and eating control my life”).

Alpha coefficients indicated good total scale reliability (total scale = .91, sub scale range .76 to .88), and 9-month test-retest reliability was excellent (total scale $r = .74$) (Table 3) (Nunnaly, 1978). In the U.S. sample, the T1-DDS total scale and subscales were significantly correlated in the expected direction with measures that assess similar emotion-related constructs, establishing the construct validity of the scales (Table 4). For example,

the T1-DDS total scale was significantly associated with PHQ8 (r = .63, p<.001), WHO5 (r = −.46, p<.001), number of complications (r = .22, p<.01), and HbA1C (r = .17, p<.01). Also, the subscales were differentially related to different criterion variables, which enhanced the validity of the assessment measure. For example, PHQ8, WHO5 and HFS-W were more strongly linked to Powerlessness than any of the other subscales, as would be expected; similarly, HbA1C was more strongly associated with Management Distress than any of the other subscales. Findings from the Canadian sample replicated all of these results.

We used HbA1C as the primary criterion for establishing clinically meaningful scale cut-points for the T1-DDS. There was a significant linear effect ($t = 2.15$, $p = .03$), but a non-significant quadratic effect, between T1-DDS and HbA1C. Furthermore, the dispersion of scores around the HbA1C mean significantly increased with the mean T1-DDS score. These findings were replicated in the Canadian sample. Along with the face validity of the response options, the findings suggest that T1-DDS mean-item cut-point scores may best be established as follows: little or no distress (1.0–1.4), mild distress (1.5–1.9), moderate distress (2.0–2.9), and high distress (≥ 3.0). Using these cut-points, 28.4% of the sample reported little or no DD, 30.0% reported mild DD, 33.7% reported moderate DD, and 7.9% reported high DD.

3.2 Areas of high and low DD

Mean levels of reported distress varied considerably across the 7 subscales, suggesting that the sample experienced higher mean levels of DD in some areas and lower levels in others (Table 3). For example, feelings of Powerlessness and Eating Distress had the highest mean levels; Management Distress, Hypoglycemia Distress and Negative Social Perceptions had midrange mean levels; and Physician Distress and Friends/Family Distress had the lowest mean levels (Table 3). These findings were fully replicated in the Canadian sample.

3.3 Associations with patient characteristics

Significant differences on T1-DDS scales occurred for several patient demographic and diabetes status variables, indicating areas of potential risk: women reported significantly higher distress on the total and all 7 T1-DDS subscales than men (total T1-DDS $t = 3.65$, $p < .001$), younger participants (median split < 41 years) reported significantly higher DD on the scale total and all 7 subscales than older participants ($t = 4.38$, $p < .001$), and those with more complications reported more distress on the scale total and all 7 subscales than those with fewer complications ($t = 3.98$, $p < .001$). Of note, those with higher BMI (≥ 25) reported significantly higher Eating Distress than those with lower BMI ($t = 3.05$, $p = .002$), those with no partner reported significantly higher Hypoglycemia Distress than those with a partner ($t = 2.09$, $p < .03$), and non-White participants reported higher Hypoglycemia Distress than White participants ($t = 2.11$, $p < .03$).

4. Discussion

This study identified seven sources of DD among adults with T1D that are significantly related to a variety of patient demographic and disease-related characteristics. The findings

are replicated in a very different, independent adult T1D sample, thus enhancing the generalizability of the results.

The seven major sources of DD among T1D adults include the following. Powerlessness points to a sense of helplessness that individuals feel when trying to exercise control over a condition that often seems uncontrollable. This is reflected in perceptions of not doing a good-enough job with diabetes, worries about long-term complications, and difficulties making sense of erratic and unexpected blood glucose numbers. Management and Eating Distress highlight specific frustrations and worries associated with key behavioral demands, such as not monitoring blood glucose enough and fears that eating constraints are controlling their life. Hypoglycemia Distress touches upon a major, ongoing source of distress that includes a lack of confidence that they will be able to identify and address hypoglycemic symptoms quickly enough to avoid embarrassment and danger, especially while sleeping or driving. Two areas of social distress also are key. These include concerns about the reactions of others when learning that they have T1D, fears that others will treat them differently, and concerns that they will be less attractive to employers (Negative Social Perceptions). Another source of DD points to the prominent role of family and friends with respect to diabetes management—that they will be under- or over-involved (the “diabetes police”) or that they will treat them as overly fragile (Family/Friend Distress). Last, distress is expressed about not receiving sufficient help, support, and understanding from their diabetes physician and health-care team (Physician Distress).

The findings indicate a far larger number of sources of DD among adults with T1D than among those with T2D. For example, the original DDS, developed primarily with T2D patients, identifies only four sources of DD: Regimen Distress, Emotional Burden, Interpersonal Distress, and Physician Distress (Polonsky et al., 2005). Thus, while some sources of distress among adults with T1D overlap with those reported by T2D patients, T1D patients experience distress in coherent patterns that are more numerous and qualitatively different from T2D patients (e.g., pervasive fears about severe hypoglycemia). Furthermore, the items that comprise what appear to be similarly titled T1D and T2D scales are different. For example, T2D patients tend to group distress about their diabetes regimen into a single, global subscale, whereas T1D patients identify and partition specific aspects of regimen distress into unique, descriptive domains. Thus, the content of the seven sources of DD for adults with T1D provides a very different set of worries and concerns than for adults with T2D.

The mean level of distress is not uniform across the seven areas of DD. Powerlessness receives the highest mean item rating, reflecting the ongoing frustrations of managing blood glucose levels when much of the variation is outside of one’s control. Eating, Management and Hypoglycemia Distress display the next highest levels, again reflecting the constant, unremitting demands of day-to-day diabetes care. The remaining three sources of distress reflect the social context of diabetes management, how it is viewed and evaluated by others, how family and friends react, and how much support is received from the diabetes health care team. Thus, the seven sources of DD for T1D adults address both distress associated with personal self-care and distress associated with the social environment in which self-care takes place.

Findings reveal a significant linear association between the total DD score and HbA1C across the entire scale distribution, including those with mild DD. Thus, DD needs to be considered across the full range of potential distress scores, from low to high. It should be noted, however, that the significant association between DD and HbA1C is based on cross-sectional findings and does not imply causality – changes in DD 'causing' changes in HbA1C or vice versa. Interestingly, previous studies have shown that DD and A1C co-vary together over time, but that changes in one do not precede changes in the other, which would suggest a causal relationship (Hessler, et al., 2014). These findings reflect the complexity of the interrelationship between the emotional side of diabetes and glycemic control, which may involve the active role of additional behavioral or physiological variables.

The analyses suggest mean-item cut-points for little or none (1.0–1.4), low (1.5–1.9), moderate (2.0–2.9), and high (≥3) distress. Using these cut-points, in our community sample of T1D adults, 41.6% report at least moderate DD, indicating the pervasiveness of DD in this population. This high rate is similar to the 45% of T2D adults drawn from similar community settings who report at least moderate distress (Fisher et al., 2012). This high prevalence reflects the pervasiveness of DD in this population and, given its significant linkages with glycemic control and self-management, highlights the need to address DD directly in clinical care.

Several patient demographic and disease-related variables provide preliminary support as indicators of risk for DD among T1D adults. For example, significantly higher DD is observed in younger than older adults, females more than males, non-White more than White patients, those with no partner more than those with a partner, and those with more complications than those with fewer or none. The significant age differences in DD may be particularly important. There is a growing literature documenting that younger adults with T2D have significantly more problems with diabetes management and glycemic control, and report higher general and diabetes-related distress than older adults with diabetes (D. M. Hessler, Fisher, Mullan, Glasgow, & Masharani, 2011; D. M. Hessler, Fisher, Mullan, & Masharani, 2010; Simmons et al., 2013). Indeed, we find similar age differences in DD among T1D patients. Younger adults with T1D, along with non-White patients and those with no partner, may require specialized, targeted interventions to address their unique personal and social needs. This points to the potential importance of directing clinical attention to the needs of specific participant subgroups—in this case, individuals who may have fewer social resources and who may in other ways feel more vulnerable than others.

These findings add to a growing literature suggesting the importance of addressing DD in clinical care for both T1D and T2D patients (Fisher, Gonzalez, & Polonsky, 2014). Even at relatively low levels, DD has been shown to be significantly related to disease management and glycemic control, and to be distinct from clinical depression (Fisher, Glasgow, & Stryker, 2010). Furthermore, the high prevalence of DD among T1D adults attests to its impact on this population. The seven sources of DD identified here, and the survey instrument for their assessment, provide a foundation for clinical intervention as part of regular diabetes care. We view DD as an expected part of having T1D and not as a co-morbid condition requiring referral or specialized care. The T1-DDS subscale scores, plus highly rated individual survey items, can be used to start a clinical conversation between

provider and patient to acknowledge the presence of emotional distress, describe it, verbalize it, normalize it, and seek ways of addressing it (Fisher, Hessler, Naranjo, & Polonsky, 2011). Often, the simple acknowledgement of DD by a trusted health care provider can ease the distress and help a patient place it in perspective (Fisher et al., 2013). Also, helping patients anticipate the distress that often accompanies future diabetes-related events, such as the emergence of new complications or the inability to meet blood glucose targets, can prevent DD from interfering with more adaptive management behaviors.

The variety of sources of DD we identified suggests that in clinical settings it may be best to administer the entire 28-item scale, rather than only selected subscales. A high total DD score may indicate overall severity, but the variability of the individual patient DD profile suggests that different individuals experience distress from different sources, with, for example, some potentially reporting only high Hypoglycemia Distress and others reporting only high Eating or Management Distress. A review of the profile of subscale scores, and highly scored individual items, can identify specific sources of distress that can direct clinical conversations and targeted interventions.

The strengths of this study are that relatively large samples of T1D adults were included; exploratory and confirmatory analyses with diverse patient samples yielded a reliable and valid DD assessment instrument for use in clinical care. Several cautions, however, should be noted. First, although some sample characteristics are similar to national statistics, confirmatory analyses with other T1D samples would be helpful, especially since the CFA fit statistics with the very different Canadian sample were only marginal. Second, the fact that our sample was more highly educated and White than national averages also suggests a need for replication with a broader sample. Last, only self-reported height and weight were used to assess BMI, which undoubtedly introduced some bias.

Adults with T1D experience sources of disease-related distress that are different from those described by T2D adults. Similar to T2D findings, the prevalence of DD in T1D adults is high and is significantly linked to glycemic control. Variation in overall levels of DD based on patient demographic and disease-related variables suggest the need for targeted, patient-directed attention to DD in clinical care.

Acknowledgements

This research was funded by NIH Grant DK094863. Portions of this study were presented as an abstract at the American Diabetes Association meetings, San Francisco, California, June 2014. Appreciation is expressed to the following for their assistance with patient recruitment: Anna Chang, M.D., Paul FitzGerald, M.D., Martha Nolte Kennedy, M.D., Grace S. Kim, M.D., Sara Kim, M.D., Pooja Sherchan, M.D., Peter M Sklarin, M.D., Amber Wheeler, M.D., Douglas W. Zlock, M.D.

References

Balfe M, Doyle F, SMight D, Screenan S, Brugha R, Hevey D, Conroy R. What's distressing about having type 1 diabetes? A qualitative study of young adults' perspectives. BMC Endocrine Disorders. 2013; 13:13–25. [PubMed: 23607267]

Cronbach LJ. Coefficient alpha and the internal structure of tests. Psychometrika. 1951; 16:297–332.

Delahanty LM, Grant RW, Wittenberg E, Bosch JL, Wexler DJ, Cagliero E, Meigs JB. Association of diabetes-related emotional distress with diabetes treatment in primary care patients with type 2 diabetes. Diabetic Medicine. 2007; 24:48–54. [PubMed: 17227324]

Dunn SM, Smartt H, Beeney L, Turtle J. Measurement of emotional adjustment in diabetic patients: validity and reliability of the ATT39. Diabetes Care. 1986; 9:480–489. [PubMed: 3769718]

Fisher L, Glasgow RE, Stryker LA. The relationship between diabetes distress and clinical depression among patients with type 2 diabetes. Diabetes Care. 2010; 33:1034–1036. [PubMed: 20150291]

Fisher L, Gonzalez JS, Polonsky WH. The confusing tale of depression and distress in patients with diabetes a call for greater precision and clarity. Diabetic Medicine. 2014; 31:764–772. [PubMed: 24606397]

Fisher L, Hessler DH, Glasgow RE, Arean PA, Masharani U, Naranjo D, Stryker LA. REDEEM: a practical trial to reduce diabetes distress. Diabetes Care. 2013; 36:2551–2558. [PubMed: 23735726]

Fisher L, Hessler DH, Naranjo D, Polonsky WH. AASAP: A program to increase recruitment and retention in clinical trials. Patient Education and Counseling. 2011; 86:372–377. [PubMed: 21831557]

Fisher L, Hessler DM, Polonsky WH, Mullan JT. When is diabetes distress clinically meaningful? Estabishing cut points for the Diabetes Distress Scale. Diabetes Care. 2012; 35:259–264. [PubMed: 22228744]

Gonder-Frederick LA, Schmidt KM, Vajda KA, Greear L, Singh H, Shepard JA, Cox DA. Psychometric properties of the Hypoglycemia Fear Survey-II for adults with type 1 diabetes mellitus. Diabetes Care. 2011; 34:801–806. [PubMed: 21346182]

Hajos TR, Pouwer F, Skovlund SE, den Oudsten BL, Geelhoed-Duijvestijn PH, Tack CJ, Snoek FJ. Psychometric and screening propoerties of the WHO-5 wellbeing index in adult outpatients with type 1 or type 2 diabetes mellitus. Diabetic Medicine. 2013; 30:63–69.

Herschbach P, Duran G, Waadt S, Zettler A, Amm C, Martin-Mittag B. Psychometric properties of the Questionnaire on Stress in Patients with Diabetes-Revised(QSD-R). Health Psychology. 1997; 16:171–174. [PubMed: 9269888]

Hessler DH, Fisher L, Glasgow RE, Stryker LA, Dickinson LM, Arean PA, Masharani U. Reductions in diabetes distress are associated with improved management and glycemic control over time. Diabetes Care. 2014; 37:617–624. [PubMed: 24170750]

Hessler DM, Fisher L, Mullan JT, Glasgow RE, Masharani U. Patient age: a neglected factor when considering disease management in adults with type 2 diabetes. Patient Education and Counseling. 2011; 85:154–159. [PubMed: 21112720]

Hessler DM, Fisher L, Mullan JT, Masharani U. Age differences in adult type 2 diabetes management and glycemic control. Diabetes. 2010; 59(Supplement 1):1435. [PubMed: 20299467]

Kroenke K, Spitzer RL, Williams JB. The PHQ-9: The validity of a brief depression severity measure. Journal of General Internal Medicine. 2001; 16:606–613. [PubMed: 11556941]

Lloyd CE, Smith J, K W. Stress and diabetes: a review of the literature. Diabetes Spectrum. 2005; 18:121–127.

Muthen, LK.; Muthen, BO. Mplus users guide. Seventh Edition ed.. Los Angeles, CA: Muthen & Muthen; 2012.

Nunnaly, J. Psychometric theory. New York: McGraw-Hill; 1978.

Ogbera A, Adeyemi-Doro A. Emotional distress is associated with poor self-care in type 2 diabetes mellitus. Journal of Diabetes. 2011; 3:348–352. [PubMed: 21883978]

Polonsky, WH. Diabetes burnouit: What you can do when you can't take it anymore. Arlington, VA: American Diabetes Association; 1999.

Polonsky WH, Anderson BJ, Lohrer PA, Welch G, Jacobson AM, Schwartz C. Assessment of diabetes-related stress. Diabetes Care. 1995; 18:754–760. [PubMed: 7555499]

Polonsky WH, Fisher L, Earles J, Dudl RJ, Lees J, Mullan JT, Jackson RA. Assesing psychosocial stress in diabetes. Diabetes Care. 2005; 28:626–631. [PubMed: 15735199]

Simmons JH, Chen V, Miller KM, McGill JB, Bergenstal RM, Goland RS, Beck RW. Differences in the management of type 1 diabetes among adults under excellent control compared with those under poor control in the T1D Exchange Clinic Registry. Diabetes Care. 2013; 36:3573–3577. [PubMed: 24026543]

Highlights

- We identify specific sources of distress around diabetes and its management for adults with type 1 diabetes.
- We report the development of a reliable and valid measure of relevant sources of distress for type 1 adults for use in clinical care and research.
- We contrast these sources with those for adults with type 2 diabetes.
- Diabetes distress among type 1 adults varies by patient demographics and disease status, and is related to glycemic control, quality of life and other diabetes-related variables.

Table 1

Participant characteristics in two diabetes samples[a]

	U.S. (*N*=305) Mean (SD) or %	Canada (*N*=109) Mean (SD) or %	Sig. (*p* Value)
Age (years)	43.21 (15.06)	41.86 (13.03)	.41
Age at type 1 diagnosis	20.71 (13.37)	15.91 (9.08)	.001
Sex (% female)	55.4%	54.1%	.81
Education			<.001
% 11–12 years	2.6%	14.8%	
% 13–16 years	48.8%	50.9%	
% 17+ years	48.6%	34.2%	
Ethnicity (% non-HispWhite)	82.2%	89.0%	.13
% married/living with partner	66.3%	79.8%	.04
Recent HbA1c			<.001
mmol/mol	58 (13.0)	64 (11.8)	
%	7.5% (1.2)	8.0 (1.1)	
Insulin method			.77
% Multiple daily injections	31.8%	30.3%	
% Pump	68.2%	69.7%	
BMI (kg/m^2)	25.41 (4.28)	27.10 (5.97)	.002
PHQ-8 Total	4.52 (4.20)	4.55 (4.64)	.95
WHO-5 Index	14.07 (4.65)	13.98 (5.33)	.87
HSF II Total Score	17.38 (12.88)	18.82 (12.90)	.32
No. of complications	2.13 (2.57)	2.72 (2.80)	.04

[a] Chi-square and *t* tests, as appropriate.

Table 2

Factor loadings (U.S. sample; N=305)[a]

	Component						
Item	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Powerlessness							
Feeling that I've got to be perfect with my diabetes management.	**.808**	.055	−.035	.091	−.100	.051	−.078
Feeling that no matter how hard I try with my diabetes, it will never be good enough.	**.753**	−.038	.058	−.122	.028	.217	.020
Feeling discouraged when I see high blood glucose numbers that I can't explain	**.886**	−.081	−.042	−.038	.017	.000	.064
Feeling that there is too much diabetes equipment and stuff I must always have with me.	**.591**	.113	.052	.029	.110	−.181	.228
Feeling worried that I will develop serious long-term complications, no matter how hard I try.	**.596**	.113	.054	.046	.097	.071	.008
Negative Social Perceptions							
Feeling like I have to hide my diabetes from other people.	−.040	**.885**	−.026	−.128	−.075	.020	.022
Feeling that people treat me differently when they find out I have diabetes.	.110	**.665**	.015	.232	−.058	−.057	.038
Feeling concerned that diabetes may make me less attractive to employers.	−.012	**.759**	−.002	−.023	.134	.109	−.063
Feeling that people will think less of me if they knew I had diabetes.	.039	**.863**	.007	.012	.033	−.007	.015
Physician Distress							
Feeling that my diabetes doctor doesn't know enough about diabetes and diabetes care.	−.083	.032	**.876**	.004	−.056	−.005	−.105
Feeling that I don't get help I really need from my diabetes doctor about managing diabetes.	.062	−.051	**.836**	−.120	.009	−.112	.099
Feeling that I can't tell my diabetes doctor what is really on my mind.	−.057	.049	**.711**	−.094	.049	.114	.128
Feeling that my diabetes doctor doesn't really understand what it's like to have diabetes.	.104	−.042	**.833**	.133	−.059	−.009	−.191
Friend/Family Distress							
Feeling that my friends or family treat me as if I were more fragile or sicker than I really am.	−.091	.022	.083	**.667**	.016	.062	.140
Feeling that my friends or family act like "diabetes police."	−.109	−.082	.076	**.693**	.125	.132	.137
Feeling that my family and friends make a bigger deal out of diabetes than they should.	.025	.065	−.108	**.888**	−.170	.001	−.076
Feeling that my friends and family worry more about hypoglycemia than I want them to.	.110	−.078	−.056	**.850**	.087	−.138	−.091
Hypoglycemia Distress							
Feeling that I don't notice the warning signs of hypoglycemia like I used to.	−.115	.001	−.044	−.148	**.803**	−.142	.211
Feeling frightened that I could have a serious hypoglycemic event while driving.	.018	−.024	−.034	.072	**.814**	.123	−.235
Feeling that I can't ever be safe from the possibility of a serious hypoglycemic event.	.114	.105	.027	−.029	**.727**	.063	−.076
Feeling frightened that I could have a serious hypoglycemic event when I'm asleep.	.088	−.047	−.009	.116	**.744**	−.120	.040
Management Distress							

	Component						
Item	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Feeling that I don't check my blood glucose level as often as I probably should.	−.320	.108	.062	.138	.031	**.743**	.115
Feeling that I am not taking as much insulin as I should.	.168	.115	−.091	−.122	−.121	**.730**	−.147
Feeling that I am not as skilled at managing diabetes as I should be.	.315	−.167	−.011	−.021	.066	**.699**	−.072
Feeling that I don't give my diabetes as much attention as I probably should.	.100	−.019	.035	.039	−.042	**.668**	.224
Eating Distress							
Feeling that my eating is out of control.	−.110	.038	−.047	−.065	.085	.049	**.888**
Feeling that thoughts about food and eating control my life.	.273	.006	.029	.090	−.110	−.194	**.721**
Feeling that I don't eat as carefully as I probably should.	.093	−.073	−.077	.031	−.056	.322	**.658**

[a] Promax rotation.

Table 3

Subscale statistics (U.S./Canada)

Distress Subscales	Number of items	Reliability α	Mean (SD)	Median	Correlation with Total Distress *R*	9–Month Test-Retest Reliability (U.S. subset)
Powerlessness	5	.87 / .87	2.84 (1.21) / 2.66 (1.26)	2.60 / 2.40	.84 / .89	.71
Negative Social Perceptions	4	.84 / .85	1.82 (1.01) / 1.97 (1.19)	1.50 / 1.50	.70 / .68	.71
Physician Distress	4	.82 / .77	1.33 (.62) / 1.32 (.63)	1.00 / 1.00	.42 / .60	.64
Friend/Family Distress	4	.80 / .76	1.49 (.69) / 1.62 (.81)	1.25 / 1.25	.66 / .62	.78
Hypoglycemia Distress	4	.79 / .75	1.98 (.97) / 1.91 (.91)	1.75 / 1.75	.64 /.71	.60
Management Distress	4	.76 / .81	1.99 (.91) / 1.87 (.94)	1.75 / 1.50	.68 / .68	.78
Eating Distress	3	.78 / .88	2.25 (1.08) / 2.34 (1.38)	2.00 / 1.67	.73 / .80	.69
Total Distress	28	.91 / .92	1.96 (.64) / 1.96 (.74)	1.86 / 1.71		.74

Table 4

Correlations with validity scales (U.S./Canada)

Distress Subscales	PHQ-8 *r*	No. Complications *r*	WHO-5 *r*	HbA1C *r*	Body Mass Index *r*	Hypoglycemia worry scale *r*
Powerlessness	.57[c] / .60[c]	.16[b] /.15	−.44[c] / −.41[c]	.10 /.15	−.04 / .09	.57[c] /.55[c]
Negative social perceptions	.44[c] /.39[c]	.06 / −.03	−.36[c] / −.38[c]	−.02 /.11	.05 / −.03	.43[c] /.59[c]
Physician distress	.18[b] /.30[b]	.12[a] / .07	−.17[b] / −.14	.12[a] /.25[b]	.06 /.05	.20[c] /.40[c]
Family/friend distress	.42[c] /.22[a]	.18[a] / −.02	−.26[c] / −.35[c]	.12[a] / −.01	.09 /.08	.43[c] /.32[b]
Hypoglycemia distress	.43[c] /.45[c]	.25[c]/.22[a]	−.27[c] / −.35[c]	−.01 /.04	−.08 / .18	.68[c] /.71[c]
Management distress	.36[c] /.49[c]	.13[b] /.23[a]	−.29[c] / −.31[b]	.39[c] /.58[c]	.06 / .07	.31[c]/.16
Eating distress	.47[c] /.58[c]	.18[b] / .26[b]	−.30[c] / −.46[c]	.17[b] / .24[a]	.25[c] / .34[c]	.34[c] / .28[b]
Total distress	.63[c] /.63[c]	.22[c] /.18	−.46[c] / −.50[c]	.17[b] /.26[b]	.08 /.17	.64[c] /.60[c]

[a] $p < .05$,

[b] $p < .01$,

[c] $p < .001$