ABSTRACT

Objective: Little data exists regarding the emerging population of adults diagnosed with type 2 diabetes (T2DM) at a younger age. This study was conducted to gain insight related to diabetes distress and self-efficacy among adults diagnosed with T2DM between 18-40 years of age.

Research Design and Methods: Individuals diagnosed with T2DM between 18-40 years of age (n = 118) completed an online survey in either English or Spanish. The survey included two validated scales to understand levels of diabetes distress and self-efficacy. Independent samples t-tests were conducted to examine differences among gender, while Pearson correlation coefficients were conducted to examine the relationships of current age, age of diagnosis, duration of diabetes, HbA1c values, and insulin use with multiple domains of diabetes distress and self-efficacy.

Results: Both regimen-related distress and interpersonal distress were reported at levels worthy of clinical attention. Overall diabetes-related distress, emotional-burden, and physician-related distress were slightly below the level of clinical significance. Bivariate analysis suggests strong positive relationships between HbA1c values and each domain of diabetes distress. Additionally, negative correlations were found between insulin use and overall diabetes distress, emotional-burden, physician-related distress, regimen-related distress, and interpersonal distress.

Conclusions: Findings suggest adults diagnosed with T2DM at a younger age experience levels of diabetes distress worthy of clinical attention, particularly regarding regimen-related and interpersonal distress. T2DM programs should include psychosocial education and communication strategies for improving social support to enhance overall quality of life for this population.
INTRODUCTION

Type 2 diabetes (T2DM) is typically considered a late-onset, adult disease; however, with the overall population rise in childhood obesity and decrease in physical activity, there has been a significant increase in the number of young adults diagnosed with T2DM [1]. An analysis of diabetes trends among American youth funded by Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH) found the prevalence of T2DM increased 21% among youth under 20 years of age from 2001-2009 [2]. Given the recent development of this population of adults diagnosed with T2DM at a younger age, little data exists regarding their general experiences. This study and its results attempt to address this shortage of data, and aims to reveal evidence of this population's interaction with physicians regarding stress factors, psychosocial health, and self-management.

Media and health care professionals typically focus on the physical complications that can result from life with T2DM. There are, however, significant psychosocial challenges associated with diabetes which are often unaddressed and warrant discussion. As the literature attests, diagnosis of T2DM can lead to emotional distress regarding lifestyle changes, adjustments with relationships, and social networks [3]. Upon receiving a T2DM diagnosis, younger adult patients (under 65 years old) were more likely to experience anxiety as a result of their diagnosis [4]. Furthermore, younger adults (18-44 years of age) with chronic diseases were also more likely to report lower social support compared to older adults, resulting in lower health-related quality of life and social well-being [5].

T2DM is a complex disease and self-management can be difficult for many. Self-efficacy, the perceived ability to perform a health behavior, is largely believed to influence the behaviors individuals adopt and maintain [6]. A study conducted by Sakar, Fisher, and Schillinger found that self-efficacy was associated with diabetes self-management behaviors across race/ethnicity and health literacy levels [7]. Another study determined greater self-efficacy predicted more frequent blood glucose testing, less frequent skipping of medication and binge eating, and closer adherence to an ideal diet in individuals living with T2DM [8]. Findings from these studies suggest self-efficacy is important for the successful management of diabetes.

Although higher self-efficacy is linked to successful diabetes management, it is important to recognize that even when diet, physical activity, and medication are properly maintained, blood sugar levels may not be effectively controlled because stress can act as a confounder. Everyday life stressors such as work deadlines and family disagreements can exacerbate diabetes management challenges [3]. It has been suggested that diabetes-related stress affects the ability to self-manage diabetes, thus negatively impacting metabolic control and psychological well-being [3, 9, 10]. Beverly and colleagues affirmed the overwhelming nature of life with diabetes in a study of T2DM patients who revealed that they often felt they could never do enough to successfully manage their diabetes. In this work, researchers noted a “sense of hopelessness characterized by an increased vulnerability” related to disease management [11, p. 1184]. Another study found participants with higher diabetes-related distress had more complications and poorer glucose control than those with lower diabetes-related distress [12]. These findings highlight the significant impact of diabetes-related distress and suggest diabetes self-care measures may cause additional stress for individuals with T2DM. In fact, researchers found diabetes distress, defined as extreme anxiety specifically related to diabetes, to be the most prevalent long-lasting factor associated with hyperglycemia in T2DM [13].

Since young adults diagnosed with T2DM represent a relatively new population, very little research has been conducted to understand the experiences of living with diabetes among this population. This research sought to investigate if and how well health care professionals were communicating with their young adult patients about their psychosocial health and gauge patients’ levels of diabetes distress, particularly in regard to regimen-related and interpersonal distress since these forms of distress significantly affect self-management efficacy.

In general, studies pertaining to diabetes tend to center around either adults with diabetes ages 55+ or children at risk for developing diabetes. Hence, the population of young adults living with T2DM is under-represented in the scientific literature. In response to this identified gap in the literature, this study describes quantitative analysis conducted as preliminary exploration of the experiences of adults diagnosed with T2DM between the ages 18-40 years.
RESEARCH DESIGN AND METHODS

Aims

The aims of this study were to assess the levels of self-efficacy and diabetes-related distress among adults diagnosed with T2DM between the ages 18-40 years.

Specific research questions included:

1. To what extent do adults diagnosed with T2DM at a younger age perceive diabetes care and management self-efficacy?

2. To what extent do adults diagnosed with T2DM at a younger age experience distress as a result of their diabetes?

Data Collection

Quantitative data were gathered through the collection of anonymous, online survey responses. The survey included pertinent demographic questions such as gender and level of education. Insulin usage, along with two validated scales to measure diabetes management self-efficacy and diabetes-related distress, were also included.

Measures

Diabetes Care and Management Self-Efficacy

Diabetes management self-efficacy among participants was determined using the short form of the Diabetes Empowerment Scale (DES-SF) [14]. This scale was designed to provide a brief, overall assessment of the self-efficacy of people with diabetes through statements such as, “In general I believe that I am able to turn my diabetes goals into a workable plan,” and “In general I believe that I can ask for support for having and caring for my diabetes when I need it.”

For the original DES, Anderson and colleagues calculated validity, reliability, and utility as a measure of diabetes-related self-efficacy [15]. Validity was established through comparison with two previously validated subscales of the Diabetes Care Profile (DCP): the DCP Positive Attitude scale and the DCP Negative Attitude scale. Additionally, factor and item analysis were conducted to develop subscales that were coherent, meaningful, and had an acceptable coefficient α. The psychometric analyses from this study (n = 375) resulted in a 28-item DES (α = 0.96) with three subscales: Managing the Psychosocial Aspects of Diabetes (α = 0.93), Assessing Dissatisfaction and Readiness to Change (α = 0.81), and Setting and Achieving Goals (α = 0.91). The correlations between the three DES subscales and the DCP Positive Attitude scale ranged from 0.32 to 0.59, indicating that patients with greater levels of self-efficacy had a more positive outlook about their diabetes. The correlations between three DES subscales and the DCP Negative Attitude scale ranged from 0.38 to 0.59, indicating that patients with greater levels of self-efficacy have a less negative outlook on their diabetes [15]. Additionally, Anderson and colleagues found the DES had positive correlations with the self-reported Diabetes Understanding scale, indicating that patients with greater levels of self-efficacy have a better understanding of diabetes [15].

To allow for brief overall assessment of diabetes-related self-efficacy, Anderson et al. developed an eight-item short form of the DES (the DES-SF) [14]. The DES-SF was created by choosing the item from the 28 DES items with the highest item to subscale correlation from each of the original conceptual domains. The reliability of the DES-SF using the original data set was α = 0.85. The DES-SF was then administered in a new study (n = 229) that resulted in a reliability of α = 0.84 [14].

Participants responded to each question on a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The scale was scored by averaging the scores of all completed items with higher scores indicating greater levels of self-efficacy.

Diabetes-Related Distress

Diabetes-related distress was examined through the Diabetes Distress Scale (DDS) which explores overall diabetes distress and is broken-down into four subscales: emotional-burden, physician-related distress, regimen-related distress, and diabetes-related interpersonal distress [16]. The validity and reliability of the DDS scale was determined through the instrument’s inclusion in a larger battery of questionnaires used in diabetes studies at four diverse sites (n = 725). Exploratory factor analysis revealed four factors consistent across sites that matched the critical content domains (emotional burden, physician-related distress, regimen-related distress, and diabetes-related interpersonal distress). The mean correlation between
the four subscales was high \( (r = 0.82) \), but the pattern of inter-scale correlations suggested that the subscales, although not totally independent, tapped into relatively different areas of diabetes-related distress. Internal reliability of the DDS and the four subscales was adequate with the overall DDS \( \alpha = 0.93 \), emotional burden \( \alpha = 0.88 \), physician-related distress \( \alpha = 0.88 \), regimen-related distress \( \alpha = 0.90 \), and interpersonal distress \( \alpha = 0.88 \). Validity coefficients yielded significant correlations with the Center for Epidemiological Studies Depression Scale, meal planning, exercise, and total cholesterol [16]. In addition, Ortiz-Parada, Baeza-Rivera, and Myers conducted a study to determine the psychometric properties of the DDS in T2DM Chilean patients using reliability analysis, exploratory factor analysis, and correlations with depressive symptoms scale. HbA1c biomarkers were conducted with a T2DM sample \( (n = 76) \) from Temuco City, Chile. The results revealed a reliability of \( \alpha = 0.74 \), a four-factor structure, and evidence for convergent validity with both the depressive symptoms scale and HbA1c marker [17]. Hence, the DDS was found to have acceptable psychometric properties that allow for the assessments of four subscales in both clinical and research settings.

The DDS is a 17-item measure that uses a Likert scale to score each statement from 1 (no problem) to 6 (a serious problem). Statements include: “Feeling that diabetes is taking up too much of my mental and physical energy every day,” and “Feeling that my doctor doesn’t give me clear enough directions on how to manage my diabetes” [16]. The authors of the DDS determined a mean item score of 3 or higher to be a level of distress worthy of clinical attention.

Participants

Participants were recruited for the study through the dissemination of flyers and advertisements via email and social media websites such as Facebook. Community partners including the American Diabetes Association, TuDiabetes, and Diabetic Living assisted with dissemination of the anonymous online survey by including information about the study in their newsletters, emails, and company Facebook pages. The online survey link was made accessible for one year, with survey reminders consistently emailed and posted to media websites throughout the year to encourage participation.

Participants self-selected to participate and were eligible if diagnosed with T2DM between the ages of 18-40, possessed English or Spanish language skills, and had access to a computer with internet services. A total of 118 individuals met the eligibility requirements with a subset of willing participants \( (n = 24) \) excluded due to missing \( (n=3) \) or incomplete data \( (n=21) \).

Research procedures were approved by the University of South Florida Institutional Review Board. Informed consent was obtained from participants. As an incentive for responding to the survey, participants were offered the opportunity to participate in a $50 e-gift card drawing with one winner selected for every twenty-five participants.

Data Analysis

The levels of both self-efficacy and diabetes-related distress were determined using the mean scores on the DES-SF and DDS. In addition, the mean scores for each distress subscale were also calculated to note specific areas of distress.

Bivariate analysis examined the relationships between current age, age at diagnosis, duration of disease, HbA1c measures, insulin use with self-efficacy, overall diabetes-related distress, and each distress subscale through Pearson correlation coefficients. Similarly, differences among men and women were examined using independent samples t-tests. All statistical analyses were performed using SPSS (IBM Corp., v. 22).

RESULTS

Participants were predominantly Caucasian females with a mean HbA1c value of 7.53 (Table 1). The mean age of participants at diagnosis was 30 and approximately half of participants used insulin to help manage their diabetes in addition to non-insulin medications.

Diabetes Care and Management Self-Efficacy

Participants reported a mean score of 3.44 (SD = .80) on the DES, indicating adults diagnosed with T2DM at a younger age feel confident in their ability to properly manage their diabetes and meet their diabetes goals. An independent samples t-test revealed no significant differences in self-efficacy between men and women. Likewise, Pearson correlation coefficients found no significant cor-
| Table 1 - Characteristics of Younger Adults Living With Diabetes |
|---------------------------------------------------------------|
| Characteristic                                               | Participants (N = 118) |
|                                                              | Frequency (n) | % Valid |
| Age in years                                                 | Mean = 38.47, SD = 8.72, Range = 18-60 |
| Age diagnosed with T2DM                                       | Mean = 30.00, SD = 8.63 |
| HbA1c at last physician visit                                | Mean = 7.53, SD = 1.76, Range = 5.0-13.3 |
| Gender                                                       | Female | 83 | 70.3% |
|                                                             | Male | 35 | 29.6% |
| Race / ethnicity                                             | White | 87 | 73.7% |
|                                                             | African American | 5 | 4.2% |
|                                                             | Latino / Hispanic | 6 | 5.1% |
|                                                             | Asian / Pacific Islander | 6 | 5.1% |
|                                                             | Native American / Alaskan Native | 5 | 4.2% |
|                                                             | Multi-racial / Multi-ethnic | 9 | 7.6% |
| Marital status                                               | Single | 36 | 31.9% |
|                                                             | Married | 63 | 55.8% |
|                                                             | Divorced | 7 | 6.2% |
|                                                             | Separated | 4 | 3.5% |
|                                                             | Widowed | 1 | .8% |
|                                                             | Other | 2 | 1.8% |
| Level of education                                           | Less than high school | 1 | .8% |
|                                                             | High school / GED | 17 | 14.7% |
|                                                             | Some college | 28 | 24.1% |
|                                                             | College degree | 43 | 37.1% |
|                                                             | Some graduate school | 9 | 7.8% |
|                                                             | Graduate degree | 18 | 15.5% |
relations between current age, age at diagnosis, duration of disease, insulin use, or HbA1c score with diabetes management self-efficacy.

**Diabetes-Related Distress**

The mean score for overall diabetes-related distress was 2.78 (SD = 1.15), below the 3.0 level of clinical significance. Likewise, the mean score for emotional-burden was slightly below the same 3.0 level of clinical significance (2.88, SD = 1.27), as was the mean score for physician-related distress (2.60, SD = 1.16). The subscales for regimen-related distress (3.26, SD = 1.40) and interpersonal distress (3.00, SD = 1.44), however, were reported at levels worthy of clinical attention.

Independent samples t-tests revealed no statistically significant differences between men and women for any of the diabetes-related distress domains. Similarly, Pearson correlation coefficients found no significant associations between current age, age at T2DM diagnosis, or duration of disease with any of the distress measures.

Pearson correlation coefficients did reveal significant correlations between HbA1c measures and each diabetes-related distress domain at the 0.01 level: overall diabetes-related distress (r = .50), emotional-burden distress (r = .56), interpersonal distress (r = .51), regimen-related distress (r = .43), and physician-related distress (r = .41) at the 0.01 level. These findings suggest a strong positive relationship between HbA1c and overall diabetes-relat-

| Table 1 - Characteristics of Younger Adults Living With Diabetes |
|---------------------------------------------------------------|
| **Health insurance coverage**                                 |
| Covered under parent plan 8 8.1%                              |
| Student health insurance plan 1 1.0%                          |
| Employer sponsored plan 77 77.8%                              |
| Medicaid 13 13.1%                                              |
| **Family members with T2DM**                                  |
| Yes 60 73.2%                                                   |
| No 22 26.8%                                                    |
| **Use of non-insulin medications to manage diabetes**         |
| Yes 58 71.6%                                                   |
| No 23 28.4%                                                    |
| **Use of insulin to manage diabetes**                         |
| Yes 43 50.6%                                                   |
| No 42 49.4%                                                    |
| **Health Professionals seen within last year**                |
| Endocrinologist 45 38.1%                                       |
| Registered nurse 27 22.9%                                      |
| Primary care physician 90 76.3%                               |
| Diabetes educator 32 27.1%                                     |
| Dietician 26 22.0%                                             |
| OB-GYN 21 17.8%                                                |
| Psychologist / Psychiatrist / Therapist 19 16.1%              |

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ed distress, emotional-burden distress, interpersonal distress, regimen-related distress, and physician-related distress. Hence, higher HbA1c measures are associated with greater levels of overall diabetes-related distress and each distress subscale. Pearson correlation coefficients also revealed weak negative relationships between insulin use and overall diabetes distress ($r = -.29$) at the 0.01 level, and emotional-burden ($r = -.24$), physician-related distress ($r = -.26$), regimen-related distress ($r = -.24$), and interpersonal distress ($r = -.26$) at the 0.05 level.

Forty-three percent of participants reported a clinically significant score of 3.0 or higher for overall diabetes-related distress. In addition, over half of the participants (57%) reported a significant score for regimen-related distress, 50% reported a significant score for interpersonal distress, and 45% reported a significant score for emotional-burden distress. These findings indicate adults diagnosed with T2DM at a younger age experience levels of diabetes distress worthy of clinical attention in relation to management regimen and psychosocial well-being.

**Correlations between Self-Efficacy and Diabetes-Related Distress**

Respondent’s level of self-efficacy was strongly correlated with overall diabetes-related distress ($r = -.46$), emotional-burden ($r = -.47$), regimen-related distress ($r = -.44$), interpersonal ($r = .39$), and physician-related distress ($r = .38$). The strong inverse relationships between self-efficacy and each domain of diabetes distress indicate lower levels of self-efficacy is associated with greater levels of diabetes-related distress.

**DISCUSSION**

Creating an anonymous online survey was useful for engaging an emerging, difficult-to-reach population. Findings from this study indicate adults diagnosed with T2DM at a younger age experience a level of diabetes distress worthy of clinical attention in relation to management regimen and interpersonal support. Additionally, results revealed a large percentage of adults diagnosed with T2DM at a younger age (43%) experience clinically significant levels of diabetes distress.

A strong, positive relationship exists between HbA1c scores and overall diabetes-related distress, emotional-burden distress, and interpersonal distress along with a moderate positive relationship between HbA1c score and physician-related distress. This indication that higher HbA1c measures are related to greater levels of diabetes-related distress is consistent with previous research. Several studies reported that life challenges associated with diabetes may cause additional stress for individuals with T2DM, resulting in a negative impact on psychological well-being and metabolic control [3, 10]. Karlson and colleagues, for example, found adults with both type 1 diabetes and T2DM experienced difficulty managing their diabetes during the winter months when diets included more enriched foods (e.g. holiday celebrations) and poorer conditions for physical activities. Participants generally did not know how to compensate for less physical activity and greater carbohydrate intake, resulting in self-blame for the poorer HbA1c value during the winter season, which negatively impacted their psychological well-being [10]. Researchers have also reported that higher HbA1c levels were associated with greater diabetes-specific emotional distress [18]. Additionally, Schabert, Browne, Mosely, and Speight found diabetes-related stigma was experienced across life domains, including at the workplace and in romantic relationships [19]. The same research found that diabetes-related stigma had a significant negative impact on psychosocial well-being; therefore, the social stigma associated with diabetes may partially account for the clinically significant levels of interpersonal distress found in this study. Young adults may be particularly vulnerable to stress from diabetes-related stigma due to new social experiences, relationships, and work environments common during young adulthood.

The association between self-efficacy and diabetes-related distress is consistent with previous findings in similar populations. Nouwin and associates found that more self-efficacious participants reported less diabetes distress in a sample of adolescents with type 1 diabetes [20]. Likewise, Delahanty and colleagues found that greater diabetes-related distress among adults with T2DM was explained by greater diabetes self-care burden and lower levels of self-efficacy [18]. Hence, individuals who felt more confident in their ability to properly manage their diabetes and reach their diabetes goals were less likely to experience high levels of diabetes-related distress.

**Strengths and Limitations**

Findings from this study should be considered in context
of certain methodological limitations. While the online survey allowed for geographic diversity, participants may not be representative of the overall population of younger adults diagnosed with T2DM. Furthermore, researchers experienced difficulty in the recruitment of males, minority populations, and those with low education levels. Due to the recent emergence of young adults with T2DM, the social stigma associated with T2DM, and the general difficulty recruiting minority populations (who are more likely to be diagnosed with T2DM) to participate in research, the sample size for this study is relatively small [19, 21, 22]. Generalizability to the larger population is therefore limited with these findings. As with all surveyed responses and self-report measures (e.g. HbA1c), there is a possibility of socially desirable responding, though data were collected anonymously to address this issue.

Offering the survey in both English and Spanish allowed for greater participant inclusion. However, few Spanish-based surveys received responses. Similarly, offering the survey online was useful for obtaining geographical diversity and allowing for greater participation, but only a relatively small number of individuals who clicked on the survey link actually completed the survey. Hence, although the ads fostered interest in the study, individuals were not necessarily motivated to participate.

Future studies should recruit a larger sample that is representative of the population of younger adults with T2DM. Researchers should consider recruiting participants from settings such as county health departments and hospital emergency rooms [23]. Future studies should also examine how diabetes-related distress, self-efficacy, and coping methods may vary depending on life-stage (e.g. college and starting a family).

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

This study provides preliminary insights into the stress experienced by younger adults with T2DM. Although participants reported confidence in their ability to manage diabetes, they also expressed levels of regimen-related and interpersonal distress worthy of clinical attention. Additionally, higher HbA1c measures were associated with greater levels of diabetes-related distress, both overall and in regards to each subdomain. This study confirms the emotional and social vulnerability young adults experience in conjunction with diabetes self-management challenges [11]. While results from this study do coincide with findings from research conducted among other populations with diabetes, it is important to note the significance of these findings in relation to young adults with T2DM.

This population has expressed needs that may not be addressed in the health care setting. To address the needs of patients, health care professionals should communicate with patients about their psychosocial health and gauge patients’ levels of diabetes distress, particularly in regard to regimen-related and interpersonal distress since these forms of distress significantly affect self-management efficacy. Interventions focusing on psychosocial issues may be useful for this population, as well as those focusing on easing the burden of the diabetes management regimen. There are many opportunities for greater understanding of this emerging population. Future studies should examine diabetes distress in young adults with T2DM using a larger, more representative population, explore effective coping mechanisms for this population, and evaluate effective intervention and communication strategies.

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