PREVALENCE OF DIABETES DISTRESS AMONG ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS

by

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Abstract

Adolescents with T1DM are at increased risk for psychological effects, including diabetes distress secondary to the constant demands of disease management combined with social and emotional stressors of adolescence. Evaluation of psychological impacts of disease management, including diabetes distress, are often not addressed during routine endocrinology visits. Early identification of diabetes distress is an essential step in the process of reducing distress.

This non-experimental, quantitative research study used the Diabetes Distress Scale (DDS), a self-reported Likert survey, to determine the prevalence of diabetes distress among adolescents with T1DM. To capture levels of diabetes distress, participants of the study included males and females of all ethnicities, English-speaking, ages 13 to 17, a diagnosis of T1DM, and Internet access to complete the study survey. Evaluation of total distress and the subcategories of emotional, regime, interpersonal, and physician burden was completed.

A total of 41 survey invitations was emailed to participants verbally expressing interest, with 28 participants responding (66%). All participants met inclusion criteria. Participants' overall mean level of diabetes distress was 2.409 (SD = 0.853) and considered "moderate distress." The emotional burden subcategory revealed the highest distress level at 3.214 (SD =1.449), thus considered "significant." Findings revealed "minimal distress" in the subcategory of physician burden, at 1.133 (SD = 0.276). Among all participants, 61% reported diabetes distress levels greater than 2.0.

Study findings provided information regarding the prevalence of diabetes distress among adolescents with T1DM receiving care in a pediatric endocrinology clinic in Southwest Virginia, which currently is not standard of care. Findings indicated that diabetes distress exists among most adolescents, and therefore, warrants routine screening as a change in practice.

Keywords: adolescents, coping, diabetes distress, diabetes distress scale, type 1 diabetes

Prevalence of Diabetes Distress among Adolescents with Type 1 Diabetes Mellitus

Type 1 diabetes mellitus (T1DM) is a chronic, autoimmune disease with devastating outcomes if not correctly diagnosed and managed. Individuals with T1DM are insulin-dependent and must continuously monitor food intake and activity and adjust insulin dosing throughout life. The Centers for Disease Control (US Department of Health and Human Services [CDC], 2020), estimates over 187,000 children and adolescents diagnosed with type 1 diabetes. Over 630,000 Virginians are diagnosed with diabetes, with 5% having T1DM (Virginia Department of Health [VDH], 2017-2018). Recent data further reveals diabetes as the seventh leading cause of death in the United States, of which 270,702 deaths were associated with underlying diabetes as initiating the chain of events leading to mortality in 2017 (US Department of Health and Human Services [CDC], 2020). These data demonstrate significant findings supporting the need for improving self-care in diabetes management across the age continuum, including adolescence.

Symptoms of depression occur twice as frequently in those living with diabetes than those without; despite the availability of screening tools, diabetes-associated depression often goes unrecognized by caregivers and medical providers (Holt et al., 2014). Those with diabetes-associated depression not only have longer-lasting episodes of depression but often experience recurrences secondary to the chronic, long-lasting nature of the disease (Holt et al., 2014). A precursor to depression includes diabetes distress, which is associated with the stressors of daily diabetes management in those living with diabetes (Kreider, 2017). Diabetes distress varies among individuals and includes symptoms of feeling overwhelmed, burned out, frustrated, and alone. Those with diabetes distress have an increased tendency for reduced glycemic control leading to poorer diabetes outcomes (Pallayova & Taheri, 2014, p. 144). Clinicians must recognize symptoms of diabetes distress early to distinguish between depression and diabetes distress in facilitating appropriate prevention and treatment (Pallayova & Taheri, 2014, p. 144). In adolescents with T1DM, one-third report having significant diabetes-related distress leading to reduced self-care such as regular glucose monitoring and insulin administration (Iturralde et al., 2017, p. 237)(Iturralde et al., 2017). These health behaviors contribute to poor glycemic control, which increases the risk of complications in addition to increased hospitalization rates and medical costs.

Evidence supports the need for effective interventions targeting the adolescent population to build necessary coping skills for reducing diabetes distress (Weissburg-Benchell et al., 2016). Although evidence supports most adolescents with T1DM report some degree of Diabetes distress, the prevalence and severity are unclear (Hagger et al., 2016, p. 2). Before developing effective interventions, identification of the prevalence of diabetes distress among adolescents with T1DM is necessary.

Purpose Statement, Research Questions

The pediatric endocrinology clinic where the study was conducted currently does not include formalized evaluation of diabetes distress in patients diagnosed with type 1 diabetes mellitus. Patients cared for in the clinic range from birth to 21 years of age, with the most frequent diagnosis of type 1 diabetes mellitus. The prevalence of diabetes distress among patients receiving diabetes care in the pediatric endocrinology clinic is currently unknown. Thus, the study aimed at determining the prevalence of diabetes distress among adolescents with T1DM. Additionally, identifying the relationship among demographic variables with survey responses defined the need to incorporate routine diabetes distress screening within the practice as a standard of care supporting American Diabetes Association (ADA) guidelines.

Diabetes distress is linked to poorer health outcomes with reduced glycemic control and self-care behaviors, including decreased self-glucose monitoring and insulin administration (Kreider, 2017). Early recognition of diabetes distress, particularly in adolescents, is an essential step in identifying stressors leading to symptom progression (Kreider, 2017). Addressing underlying stressors contributing to suboptimal diabetes management is achievable through several screening tools, including the Diabetes Distress Scale (DDS) supported by the Behavioral Diabetes Institute (Diabetes Distress Scale, 2005). Evidence from using the DDS supports findings that elevated distress scores are reported among younger individuals, including feelings of being more depressed, thus using insulin less often and demonstrating overall reduced diabetes self-care (Polonsky et al., 2005).

This study attempted to answer the following research questions:

1. In adolescents with type 1 diabetes mellitus, what is the prevalence of diabetes distress?
2. To what extent do adolescents with type 1 diabetes mellitus experience diabetes distress?
3. What characteristics of adolescents with type 1 diabetes mellitus are associated with diabetes distress?

Study Variables

The independent variable of the study was the Diabetes Distress Scale. The dependent or outcome variable was diabetes distress, as measured through the DDS scale. Additional secondary variables included diabetes distress related to four subcategories: emotional burden, regime, interpersonal, and physician distress. Demographic variables included age, gender, ethnicity, duration of diagnosis, type of insulin administration (i.e., pump vs. multiple daily injections), and glucose monitoring modality (i.e., fingerstick glucometer vs. continuous glucose monitoring).

Study Implementation

Study participants completed an online survey regarding the perceived level of distress using the Diabetes Distress Scale. Participants and caregivers received information regarding the study's purpose and provided both assent and consent before taking the survey. Individualized survey links were emailed to the participants' email addresses to complete at their convenience.

LITERATURE REVIEW

Search Strategies and Results

The database search of COCHRANE, PubMed, and CINAHL included the keywords of adolescents, coping, type 1 diabetes, and diabetes distress scale. An additional search using Google Scholar identified studies performed by Drs. Fisher and Polonsky who are the key contributing authors of the DDS. Studies reviewed are written in English, published between 2003 and 2020, with the full-text available relevant to the topic of interest. After reviewing abstracts and full text of articles, a total of eight studies were selected for the final analysis of the literature review.

Levels of Evidence

The studies selected for review were relevant to the topics of evaluating and addressing diabetes distress in adolescents with T1DM. Multiple levels of scholarly review were obtained, including systematic reviews, cohort studies, and randomized controlled trials evaluating the effects of diabetes management among adolescents with T1DM. The reviewed studies supported the study purpose in attempting to determine diabetes distress prevalence among adolescents with T1DM.

Synthesis of Evidence

Diabetes Distress & Health Outcomes

Diabetes distress is defined as an "emotional state where people experience feelings such as stress, guilt, or denial that arise from living with diabetes and the burden of self-management" (Kreider, 2017, p. 1). Diabetes distress increases over time and does not go away on its own, and if left unaddressed, it can become chronic (Fisher et al., 2019, p. 806). A review of adults with T1DM reported 43% indicated "significant distress" related to diabetes management (Fisher et al., 2019, p. 806). Daily symptoms of diabetes distress vary in intensity and frequency, leading to spontaneous emotional reactions, concerns for long-term complications, and fear of hypoglycemia (Pallayova & Taheri, 2014, p. 144). If symptoms are left unchecked, emotions and behaviors may spiral into worsening diabetes self-management, thus worsening health outcomes (Pallayova & Taheri, 2014). Among adolescents, a systematic review revealed that, like adult studies, many adolescents report diabetes distress, with nearly one-third indicating significant distress levels (Hagger et al., 2016, p. 10). Also, adolescents aged 14 to 18 years of age report higher levels of diabetes-related distress than younger counterparts placing this group at increased risk (Hagger et al., 2016, p. 9).

Risk Factors

Managing type I diabetes mellitus in adolescents is challenging and multifaceted for patients, caregivers, and the healthcare team. Evidence supports that adolescents are at a higher risk for poor diabetes control secondary to many factors, including demands of the disease, social implications, and psychological factors (Iturralde et al., 2017). Developmentally, adolescents are in a transitional stage, attempting to gain more independence and less reliance on parents. Trying to keep up with the demands of daily diabetes management mixed with developmental concerns and everyday life often leads to diabetes distress (Iturralde et al., 2017).

Demographics and Diabetes Distress

The systematic review of these studies revealed common reports of diabetes distress among adolescents, but mixed findings related to demographics and sources of distress (Hagger et al., 2016). A few studies revealed that females tend to have avoidant coping styles leading to higher diabetes-related distress scores than males, while others revealed no significant differences (Hagger et al., 2016 & Iturralde et al.,2017). While most studies found no relationship between age and level of diabetes distress, others found that those between the ages of 14 and 18 reported higher distress than those older than 18 (Hagger et al., 2016). Regarding ethnicity concerning diabetes distress, studies found no significant associations except one study, which revealed minority backgrounds experiencing more considerable distress than White peers (Hagger et al., 2016).

Adolescent Diabetes Distress Characteristics

As previously described, diabetes distress severity varies among individuals; thus, it may be considered an expected response to having diabetes in some individuals, and therefore not routinely recognized or addressed by caregivers (Fisher et al., 2019 & Iturralde et al., 2017). Although diabetes distress occurs most commonly among those with poor glycemic control, it may also occur in those with relatively reasonable glycemic control as well (Fisher et al., 2019)(Fisher et al., 2019). Therefore, combined with a lack of routine screening, diabetes distress in adolescents may be interpreted as a normal response to chronic disease and not addressed.

Adolescent Coping Strategies

Overall studies indicated adolescents reported levels of distress mostly related to interpersonal, social, and family support (Hagger et al., 2016). Adolescents with T1DM tend to use a variety of ways to cope with stressors. Evaluation of the effect of diabetes self-care behaviors among adolescents with T1DM included a review of coping styles in determining the impact of self-care behaviors in diabetes management such as frequency of blood glucose monitoring and HgbA1c levels (Hilliard et al., 2013 & Iturralde et al., 2017). The researchers determined that adolescents typically use a more avoidant strategy by disengaging and downplaying the disease's seriousness (Iturralde et al., 2017, p. 237).

ADA Practice Guidelines and Diabetes Distress

The ADA publishes guideline recommendations for diabetes management annually. The most recent guidelines recommend clinicians consider screening for diabetes distress "at diagnosis and during routine follow-up care, (to) assess psychosocial issues and family stresses that could impact diabetes management and provide appropriate referrals to trained mental health professionals, preferably experienced in childhood diabetes" (ADA, 2020, Recommendation 13.9). An additional recommendation encourages clinicians to "assess youth with Diabetes for psychosocial and diabetes-related distress, generally starting at 7–8 years of age (ADA, 2020, Recommendation 13.13). Despite recommendations and efforts in improved diabetes management, diabetes-related complications still occur due to many clinicians having limited resources, time, or confidence in addressing diabetes distress during routine office visits (Pallayova & Taheri, 2014). This concern makes evidence-based management of the disease challenging, particularly in vulnerable populations such as adolescents. Therefore, incorporating the evaluation of barriers to diabetes management, leading to diabetes distress allows clinicians to meet recommended guidelines of evidence-based care.

Screening for Diabetes Distress

As current literature supports, adolescents with T1DM have varying levels of diabetes distress, thereby supporting the need for further studies to identify diabetes distress in adolescents with type 1 diabetes mellitus. Early recognition of diabetes distress, particularly in high-risk adolescents already faced with emotional stressors, is an essential step in reducing complications and symptom progression, including significant depression leading to worsening outcomes (Kreider, 2017). Diabetes distress is often not addressed during routine endocrinology visits, nor are many providers willing to address this concern during visits (Fisher et al., 2019).

Experts recommend that diabetes distress evaluation be considered even among those not experiencing significant signs of distress (Fisher et al., 2019). There are limited self-rating scales addressing diabetes distress in the adolescent population, with mixed results noted from a systematic review (Hagger et al., 2016). Tools supported by the Behavioral Diabetes Institute offer various scales for evaluating diabetes distress in both type 1 and type 2 diabetes, yet few currently target adolescents.

Diabetes Distress Interventions

Evidence suggests that while many self-scoring scales assist with identifying levels of diabetes distress, few studies target interventions to reduce elevated diabetes distress levels (Sturt et al., 2015). Early recognition of symptoms of Diabetes distress is a crucial component of successful interventions (Pallayova & Taheri, 2014). The T1D-REDEEM trial compared interventions in reducing diabetes distress and suggested that diabetes distress among adults with T1DM can be reduced through interventions (Fisher et al., 2018). Evidence supported the use of the T1-DDS scale in an adult study revealed significant reductions in overall scores for total distress and seven subscales, including powerlessness, management distress, hypoglycemia distress, negative social perceptions, eating distress, physician distress, and family/friend distress (Fisher et al., 2018). Most evidence involving adults and adolescents with T1DM diabetes-related distress strongly supports the need to identify and address diabetes distress early, in addition to offering interventions. Yet, the literature search revealed limited evidence suggesting precise interventions.

Summary

In summary, articles from the critical appraisal involved reviewing factors associated with diabetes distress and its effect on self-care behaviors among adolescents with T1DM. An analysis of the literature suggests the demands of diabetes management are associated with varying levels of diabetes distress, which may lead to suboptimal glycemic control and poor health outcomes. Therefore, identifying the prevalence of diabetes distress is warranted, with routine evaluation incorporated into the standard of care. This study evaluated the prevalence of diabetes distress among adolescents with T1DM using the DDS scale as an initial step in identifying the need for routine diabetes distress screening in a pediatric endocrinology clinic.

THEORETICAL/CONCEPTUAL FRAMEWORK

The health promotion model (HPM) is a relevant theoretical model for the research study by evaluating the perception of diabetes distress among adolescents with T1DM. Nola Pender’s HPM focuses on enhancing one’s wellbeing through health-promotion activities incorporating interpersonal and situational influences and developing improved self-efficacy, thus reducing one’s perception of barriers limiting behavior (Polit & Beck, 2017, p. 123). In nursing, the HPM guides the understanding of an individual’s behavior by offering ideas to promote healthy lifestyles (Pender, 2011, p. 2).

This model also suggests that one’s health behavior is often influenced by background factors, including several essential beliefs. These critical beliefs include 1) perceived benefits/barriers to action and self-efficacy, 2) activity-related effect, 3) interpersonal/situational influences, 4) commitment to a plan of action, and 5) immediate competing demands and preferences (Pender, 2011, p.4). Through the collaboration of these critical beliefs among the nurse and patient, healthy lifestyle behaviors are achievable (Pender, 2011).

Most adolescent behavior is self-driven and significantly influenced by peers and environmental aspects, both physically and socially. Although adolescents with T1DM cannot control developing the disease, their ability to adapt is often influenced by many factors they can control. As the HPM proposes, individuals may change behavior if they can develop confidence in that behavior, having a positive outcome (Polit & Beck, 2017).

Two assumptions of the HPM applied to this study: 1) “persons have the capacity for reflective self-awareness, including assessment of their own competencies” and 2) “individuals seek to actively regulate their own behavior” (Pender, 2011, p. 5). When adolescents can identify areas of stress related to diabetes self-management, they can focus on personalized goals of diabetes distress reduction. Additionally, theoretical propositions from the HPM relate to the concepts of this research. The first suggests that “perceived barriers can constrain commitment to action, a mediator of behavior as well as actual behavior” (Pender, 2011, p. 5). The second proposition suggests “greater perceived self-efficacy results in fewer perceived barriers to a specific health behavior” (Pender, 2011, p. 5). When adolescents identify areas of distress related to diabetes management, such as emotional or regime distress, they are better equipped to target interventions aimed at reducing this distress.

METHODOLOGY

Study Design

This non-experimental, quantitative research study used the Diabetes Distress Scale (DDS), a self-reported survey, to determine the prevalence of diabetes distress among adolescents with T1DM receiving care in a pediatric endocrinology clinic in Southwest Virginia (Diabetes Distress Scale, 2005).

Study Subjects & Settings

The study setting involved an outpatient pediatric endocrinology practice located in Southwest Virginia with four clinical providers managing patients from birth to 21 years of age. The clinic serves patients living within 150 miles radius of Roanoke, Virginia. The most prevalent disease condition seen in the practice is type 1 diabetes mellitus. To capture levels of diabetes distress, participants of the study included males and females of all ethnicities, English-speaking, ages 13 to 17 years of age with a diagnosis of T1DM, and access to the Internet to complete the study survey.

Study Procedures

Recruitment

To recruit participants, study information flyers were displayed in the pediatric endocrinology clinic and exam rooms. Clinicians within the practice also discussed eligibility with patients during routine office visits. A locked drop box was available for participants to place study interest forms, which only the researcher could access. The researcher contacted interested participants either in person during the clinic visit or on the phone to discuss eligibility and obtain consent and assent. Examples of the recruitment flyer and study participant information forms are in Appendix D and E.

Study Instrument

A variety of self-assessment scales aid clinicians in identifying both depression and diabetes distress. The DDS is a helpful scale for evaluating the level of overall diabetes distress and additional factors associated with diabetes management in adults with type 2 diabetes (Fisher et al., 2019). A systematic review of studies targeting adolescents using scales other than the DDS revealed reports of diabetes distress (Hagger et al., 2016), yet questions the validity of those scales as cut-offs for the scores are based on adult measures. With limited data available for scales aimed at children and adolescents, the DDS demonstrated internal reliability and validity in several studies with survey questions adaptable to adolescents (Polonsky et al., 2005).

The DDS initially developed for type 2 diabetes is designed to assess several domains, including total distress along with emotional burden, psychosocial, regime, and physician distress, and has been used internationally as an instrument for initiating discussion regarding diabetes distress (Diabetes Distress Scale, 2005). The DDS scale supports clinical research through the ability to obtain quantitative data, which is helpful for immediate and longitudinal evaluation of changes in distress over time (Fisher et al., 2019). While there is a longer 28-item T1-DDS standardized for adults with T1DM, several questions on the scale do not relate to many adolescents, such as work and driving experiences.

The DDS provides a consistent and generalizable factor structure along with good internal reliability ($\alpha > 0.87$) and validity with the Center for Epidemiological Studies Depression Scale across several studies, thus was chosen as the preferred study instrument for the research study (Polonsky et al., 2005, p. 630). The copyrighted DDS scale is a 17-item Likert-scale self-report survey available free of charge for non-profit institutions in clinical care and research, with access to completion and scoring available at www.diabetesdistress.org (see APPENDIX A). The DDS scale scores were used to measure the baseline degree of total diabetes distress and four subscales, including emotional, regime, interpersonal, and physician burden, which aided in categorizing specific areas of concern.

The DDS scores evaluated total diabetes distress as well as distress in the following subscales:

1) Emotional burden (5 items) reflecting the participants' level of diabetes distress such as feeling overwhelmed, frightened, or fearful about the management of diabetes over time (items 1, 3, 8, 11, and 14)
2) Regime distress (5 items) reflecting the participants' level of diabetes distress related day to day management, including meal planning and exercise (items 5, 6, 10, 12, and 16)
3) Interpersonal distress (3 items) reflecting the participants' level of diabetes distress related to support for their diabetes from family and friends (items 7, 13, and 17)
4) Physician distress (4 items) reflecting the participants level of diabetes distress related to healthcare and obtaining enough expertise, support, and direction from their healthcare provider (items 2, 4, 9, and 15)

Mean scores are determined for total distress along with the four subcategories. Scores ranged from minimal to significant risk, as outlined in Table 1. According to the survey recommendations, any score higher than 2.0 is considered "clinically significant," with intervention recommended (Diabetes Distress Scale, 2005).

Table 1 Diabetes Distress Scores

DDS Score	Level of Distress
< 2.0	Minimal risk
2.0 – 2.9	Moderate risk
> 3.0	Significant risk

Data Collection

Data collection occurred over 8 weeks. Participants completed the DDS survey following consent and assent to the study. An automatically generated email reminder was sent during the second week to all participants who had yet to complete the survey. During the seventh week of implementation, participants yet to respond received a final email reminder to complete the survey. Participants completed the survey by self-ranking their perception of diabetes distress over the previous 2 months on a Likert scale from 1 to 6, with 1 indicating no distress and 6 indicating significant distress. Due to the de-identification of survey data during analysis, participants did not receive score results upon survey completion. In allowing participants a way to review their potential scores, after survey completion, participants were emailed the link if they desired to complete the DDS online, review their scores, and discuss results with their diabetes providers. Participants scoring high levels of distress were encouraged to seek psychological services for further evaluation and treatment. If high scores resulted in critical concerns for participants’ immediate health and safety, the researcher encouraged an immediate intervention.

Protection of Human Subjects

Approval was obtained before implementation by the Carilion Clinic Institutional Review Board (IRB), with Radford University IRB ceding to the Carilion IRB. Participants received study information in-person or via telephone consent with the lead research team member. Information provided to parents and participants included study purpose and overview, procedure, the required time for participation, and participant eligibility. Participants were offered a written copy of the information if desired. Following consent and assent, the participants' email addresses were confirmed and entered into the REDcap (research electronic data capture) survey database. Approval and support from the clinical setting stakeholders, including physician and administrative leader support, were obtained.

Data Storage & Security

Patient confidentiality and protection of information following data collection were ensured through Carilion Clinic's REDcap. Carilion Clinic's REDcap software was used as the central location for data storage. REDCap provided a secure, web-based application designed to support data management and collection for research/QA/QI studies. Carilion Clinic's REDCap servers are securely housed on site in a limited access data center, and all data are stored on Carilion's firewall-protected network.

The Health Analytics Research Team (HART) supported the proper development of the survey into REDCap, observing appropriate change control and enforcing appropriate security controls. The data collection project was built with a study-specific data dictionary, enforcing intuitive, accurate, consistent, and complete data entry. REDcap provided a survey tool for creating and managing the online survey of which the DDS was built, including the desired demographic information. HART restricts user access to the IRB-approved project research team utilizing the approved processes and standards of the Technology Services Group.

REDcap is HIPAA compliant and provides audit trails. Data can be easily exported in several formats to a secure network directory for combination with extracted data, if appropriate, and analysis with common statistical packages. Following IRB approval, data for the research study was de-identified, entered into an Excel spreadsheet, and saved on the study's secured shared drive created by HART. A biostatistician research specialist from Carilion Clinic assisted with data analysis and extraction from REDcap using Statistical Analysis Software program.

Email addresses and information, including demographic variables such as age, gender, ethnicity, insulin administration, and glucose monitoring modality, were gathered from participants through an online REDcap survey. Email addresses connected survey results and data in REDCap but were de-identified before analysis and were not visible to the researcher. After 3 years, all data will be destroyed from the REDcap database.

Statistical Analysis

The DDS scores were used to assess the total perceived distress among participants and identify subscale distress in areas relating to psychosocial, emotional, regime, and physician distress. Results were used to determine the prevalence of diabetes distress among adolescents receiving care in a pediatric endocrinology clinic in Southwest Virginia. The comparison of demographics related to age, gender, length of diabetes diagnosis, insulin administration, and glucose monitoring was also evaluated relative to diabetes distress.

The primary outcome of interest was the prevalence of diabetes distress. The primary outcome was analyzed to determine the prevalence of distress among participants completing the survey. A descriptive analysis was included to investigate categorical variables by frequencies and counts plus numeric variables by central tendency and variation. Additional variables collected and analyzed included gender, age, type of insulin (i.e., insulin pump vs. injections), and glucose monitoring type (i.e., glucometer vs. continuous glucose monitor). For the research study, variable relationships or differences were investigated through t-tests. A Bonferroni correction was used to adjust the p-value to 0.0125 for statistical significance from 0.05 with tests two-sided when appropriate. Diabetes distress scoring was divided into subcategories, including emotional burden, regimen distress, interpersonal distress, and physician distress. These secondary outcomes were tested similarly to overall diabetes distress.

RESULTS

The study survey aimed at identifying the prevalence of diabetes distress among adolescents with T1DM receiving care in a pediatric endocrinology clinical setting in Southwest Virginia. In the study, data collection included determining DDS scores in evaluating the existence and level of reported diabetes distress among individuals who completed the survey. Demographics including age, gender, years with diabetes diagnoses, insulin, and glucose monitoring modality were also correlated with distress scores.

The overall mean level of diabetes distress reported among all participants was 2.409, with a standard deviation of 0.853. The subcategory with the highest mean level of reported diabetes distress among all participants involved emotional burden, at 3.214 (standard deviation 1.449). The subcategory reporting the lowest mean level of diabetes distress was physician distress, at 1.133 (standard deviation of 0.276). These findings revealed that participants reported overall a degree of diabetes distress categorized as “moderate distress.” Results also showed that participants reported a higher degree of “significant distress” in the emotional burden subcategory. Participants reported no significant distress regarding the perceived level of physician support, thus indicating they felt supported by their healthcare team (Table 2).

Table 2 Adolescent DDS Scores by Category

Distress Type	**Comparison Variable**	**Group 1 Mean and Std Dev**	**Group 2 Mean and Std Dev**	**P-value**	**Significance (<0.0125)**
Overall Distress	Age Category	13-15 years: 2.04 (0.76)	16-17 years: 2.84 (0.77)	**0.0108**	*
	Years with T1DM	0-5 years: 2.39 (1.03)	6-12 years: 2.42 (0.67)	0.9468	
	Gender	Females: 2.62 (0.86)	Males: 1.87 (0.58)	0.0332	
	Insulin Type	Injections: 1.81 (0.60)	Pump: 2.54 (0.85)	0.0826	
Emotional Burden	Age Category	13-15 years: 2.55 (1.27)	16-17 years: 3.98 (1.28)	**0.0063**	*
	Years with T1DM	0-5 years: 3.27 (1.76)	6-12 years: 3.15 (1.12)	0.8392	
	Gender	Females: 3.56 (1.45)	Males: 2.35 (1.10)	0.0436	
	Insulin Type	Injections: 2.00 (0.42)	Pump: 3.47 (1.46)	**0.0004**	*
Physician Burden	Age Category	13-15 years: 1.05 (0.10)	16-17 years: 1.23 (0.37)	0.1147	
	Years with T1DM	0-5 years: 1.12 (0.07)	6-12 years: 1.25 (0.35)	0.0231	
	Gender	Females: 1.18 (0.31)	Males: 1 (-)	0.0148	
	Insulin Type	Injections: 1.05 (0.11)	Pump: 1.15 (0.30)	0.4639	
Regimen Burden	Age Category	13-15 years: 2.17 (1.83)	16-17 years: 2.95 (2.25)	0.0447	
	Years with T1DM	0-5 years: 2.60 (1.85)	6-12 years: 1.27 (0.57)	0.7372	
	Gender	Females: 2.64 (1.08)	Males: 2.27 (0.66)	0.3840	
	Insulin Type	Injections: 2.20 (0.73)	Pump: 2.61 (1.03)	0.4089	
Interpersonal Burden	Age Category	13-15 years: 2.29 (1.64)	16-17 years: 2.87 (1.29)	0.3103	

	Years with T1DM	0-5 years: 2.45 (1.51)	6-12 years: 2.67 (1.52)	0.7104	
	Gender	Females: 2.95 (1.56)	Males: 1.58 (0.64)	**0.0029**	*
	Insulin Type	Injections: 1.87 (1.59)	Pump: 2.71 (1.46)	0.2595	

*indicates statistical significance with $p < 0.0125$ based on Bonferroni correction

Age Distribution

The participants' age distribution was divided into groups: Group A, including ages 13 through 15 years, and Group B, including ages 16 through 17 years. Among participants' ages, 13 through 15 years, the mean diabetes distress level was reported at 2.04 (SD = 0.76) and ages 16 through 17 years of 2.84 (SD = 0.77). There was evidence to suggest a significant difference in mean overall distress for age categories ($p = 0.0108$), with older adolescents reporting higher levels of distress. Also, there was evidence to suggest a significant difference in the mean level of emotional distress among age groups with $p = 0.0063$ (Group A = 2.55, SD= 1.27; Group B = 3.98, SD= 1.28). These subcategory results indicated that among adolescents completing the survey study, older teens reported not only a higher degree of total diabetes distress but significant emotional distress as well.

Gender

In this study, participants were primarily female, with 20 responding (71.43%) compared with only eight males (28.57%) (Table 3). The mean diabetes distress levels were higher among female participants (2.62, SD = 0.86), with male participants scoring an average of 1.87 (SD = 0.58) yet considered insignificant with a *p*-value of 0.0332. There was a significant difference among gender in relation to level of interpersonal distress among participants (females = 2.95, SD = 0.64; males = 1.58, SD = 0.64; $p = 0.0029$). This finding suggested that females reported an increased difficulty regarding interpersonal relationships compared with males.

Table 3 Response Frequency by Gender

Gender	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Females	20	71.43	20	71.43
Males	8	28.57	28	100.0

Diagnosis Duration

There was no significant difference in total diabetes distress related to the duration of type 1 diabetes mellitus diagnosis among the age groups (*p* = 0.9468). Although not statistically significant, older survey respondents ages 16 through 17 years with T1DM diagnosis duration longer than 5 years reported a higher degree of diabetes distress regarding physician and interpersonal burden than those with a diagnosis less than 5 years. Regime and emotional burden were reported at higher distress levels among younger respondents ages 13 through 15 years and with a shorter diagnosis duration of fewer than 5 years.

Insulin Modality

Although statistically insignificant (*p* = 0.0826), study respondents using insulin pumps reported higher overall diabetes distress scores (2.54, SD = 0.85) compared with those using multiple daily injections (1.81, SD = 0.60). Additional findings regarding emotional distress revealed a significant difference among insulin delivery groups, with pump users indicating a higher distress level of 3.47 (SD = 1.46) than those using injections (2.00, SD = 0.42) with a *p* = 0.0004. This finding indicated those adolescents using insulin pumps perceived daily diabetes management as more stressful than multiple daily injections, although most survey respondents, 23 out of 28 or 82.14%, used insulin pumps.

Glucose Monitoring

Most participants completing the survey reported using continuous glucose monitoring, including 26 participants, or 92.86%. Only two participants reported using standard fingerstick glucometers (7.14%).

Emotional Burden and Coping

Overall emotional burden among all participants completing the study was considered moderate (Table 4). Areas of concern reported by adolescents included feeling that diabetes takes up too much mental and physical energy and being overwhelmed with feeling diabetes controls their lives. Findings from this study support prior studies with overall levels of diabetes distress among adolescents with T1DM regarded as moderate. These results indicated that adolescents receiving care in the pediatric endocrinology clinic are at risk for ineffective coping mechanisms leading to suboptimal diabetes management due to increased emotional burden related to diabetes management. Adolescents with diabetes distress and inadequate coping mechanisms avoid tasks related to diabetes management, including glucose monitoring and insulin administration, thus leading to poor glycemic control and worsening outcomes (Hilliard et al., 2013, p. 32).

The demands of diabetes management create an enormous responsibility for patients and families. Results from the study indicate that most adolescents with T1DM experience diabetes distress, of which they and their caregivers may be unaware. These findings support a relationship among diabetes management, emotional burden, and coping strategies among adolescents with T1DM. Available rating scales for adherence to diabetes management have revealed avoidant coping styles observed among adolescents with T1DM associated with reduced self-care behaviors (Iturralde et al., 2017). One study described the relationship between diabetes distress with high overall diabetes distress scores among youth living with T1DM (Lasaite et al., 2016)

Table 4 Adolescent Diabetes Distress Subcategories

Adolescent Diabetes Distress: Ages 13 through 17 years **(n = 28)**(Hilliard et al., 2013, p. 32)	
Subcategory	**Mean Score**
Emotional Burden	**2.543**
Feeling that Diabetes is taking up too much of my mental and physical energy every day	3.143
Feeling angry, scared, and/or depressed when I think about living with Diabetes	2.214
Feeling that Diabetes controls my life	2.964
Feeling that I will end up with serious long-term complications, no matter what I do	1.071
Feeling overwhelmed by the demands of living with Diabetes	3.321
Interpersonal Distress	**2.916**
Feeling that friends or family are not supportive enough of self-care efforts (e.g., planning activities that conflict with my schedule, encouraging me to eat the “wrong” foods)	3.25
Feeling that friends or family don’t appreciate how difficult living with Diabetes can be	3.036
Feeling that friends or family don’t give me the emotional support that I would like	2.464
Regime-related Distress	**2.371**
Feeling that I am not testing my blood sugars frequently enough	1.071
Feeling that I am failing with my diabetes routine	2.107
Not feeling confident in my day-to-day ability to manage Diabetes	3.286
Feeling that I am not sticking closely enough to a good meal plan	2.679
Not feeling motivated to keep up my diabetes self-management	2.714
Physician-related Distress	**1.911**
Feeling that my doctor doesn’t know enough about diabetes and diabetes care	1.25
Feeling that my doctor doesn’t give me clear enough directions on how to manage my Diabetes	3.071
Feeling that my doctor doesn’t take my concerns seriously enough	2.18
Feeling that I don’t have a doctor who I can see regularly enough about my Diabetes	1.143

Interpersonal Distress

This study revealed that interpersonal distress was the most concerning area among adolescents completing the study survey. Areas of concern regarding interpersonal relationships included feeling that family and friends were unsupportive and did not appreciate how difficult living with diabetes can be. This study cannot conclude the source of distress concerning interpersonal relationships based on these findings. Common problems during adolescence include feeling less heard while attempting to gain independence from parents. Studies indicated that adolescents reported higher levels of diabetes distress with reduced support from family members (Hagger et al., 2016). Additional study findings suggest increased parental distress if parents believe their teen cannot manage day-to-day diabetes management tasks and, therefore, remain involved, despite adolescents feeling they are themselves responsible (Law et al., 2013).

Regime-related Distress

The third-highest scoring subcategory of this study involved regime-related distress. The biggest concern for adolescents completing the study survey involved feelings of low confidence in maintaining day-to-day diabetes self-management. Adolescents also reported not feeling motivated to keep up with diabetes self-management. Prior studies suggested that diabetes distress reduction is not always reflected as an improvement in self-management behaviors or glycemic control as diabetes distress alone may be a barrier for motivation (Fisher et al., 2019, p. 807). This finding supports the need to identify underlying levels of diabetes distress and barriers to diabetes management in reducing distress for improving outcomes. Regarding the response to interventions aimed at improving behavior, those reporting symptoms of diabetes distress without subsequent depression were more receptive to initiating behavior changes and improving self-efficacy (Sturt et al., 2015, p. 101).

Physician-related Distress

Adolescents completing the study survey indicated minimal distress regarding physician-related distress. Interestingly, the biggest concern reported within this category involved feeling that their physician did not provide clear enough directions on managing their diabetes. This finding indicates the need for providers to engage adolescents in the plan of care and ensure that realistic goals are established and communicated. Although minimal research has been conducted in evaluating adolescent diabetes distress, evidence suggests that this population feels that talking to their providers about diabetes distress is impactful and should be incorporated into routine care (Morrissey et al., 2020, p. 537).

Diabetes Distress and Gender

The results from the study supported previous evidence with females reporting higher levels of overall diabetes distress in addition to regime, emotional, physician, and particularly interpersonal burden compared with male counterparts. Similar to comparable studies, this study involved a more significant proportion of females to males. It cannot be determined whether the higher female ratio in the study is related to sample selection or if females are more willing to discuss feelings over their male peers. A systematic review of studies evaluating adolescent diabetes distress revealed three out of 11 studies suggesting females having higher distress than peers (Hagger et al., 2016, p. 9).

A Lithuanian-Swiss study provided additional evidence supporting a clinical significance of increased diabetes distress among adolescent T1DM female participants compared with males (Lasaite et al., 2016). In Sweden, more than half of female respondents ages 15 through 18 years indicated moderate to significant levels of diabetes distress compared with males (Forsander et al., 2016, p. 651). Prior studies demonstrated that females tend to have avoidant coping styles leading to higher diabetes-related distress scores than males, while others revealed no significant differences (Hagger et al., 2016; Iturralde et al., 2016). Little is known as to the reason for increased distress reported among females, which questions whether results are an actual increase or a result of different coping styles among gender (Morrissey et al., 2020).

Diabetes Distress and Age

This study supported prior studies revealing a variation in levels of diabetes distress among adolescents with T1DM relative to age. Results suggested that older adolescents in Group B (ages 16 through 17 years) reported higher levels of diabetes distress than their younger counterparts. Adolescents have increased pressure to feel "normal" and struggle with gaining independence in preparing for early adulthood. Although it is unclear as to the cause of increased distress among older adolescents in this study, an assumption includes the stage of development as a contributing factor. Mixed studies found no relationship between age and level of diabetes distress, while others found adolescents ages 14 through 18 reported higher distress than those older than 18 years (Hagger et al., 2016). There are limited studies evaluating diabetes distress among individuals with type 1 diabetes mellitus, particularly among adolescents and young adults. Most results faired older adolescents and those entering early adulthood, thus supporting the need to identify distress in younger teens to thwart problems later (Lasaite et al., 2016).

Diabetes Distress and Insulin Modality

Unlike results from the literature, participants using insulin pumps in this study indicated higher overall diabetes distress and subcategory scores than those using multiple daily insulin injections, yet the subcategory was statistically insignificant except for emotional burden. These findings may be related to the higher incidence of insulin pump use among survey participants completing the study (82.14%) than those using multiple daily injections. Therefore, a conclusion about insulin modality concerning diabetes distress levels cannot be inferred from these study findings. It does appear from these results that participants using insulin pumps reported higher levels of emotional distress, which include factors such as feeling that diabetes takes up too much daily energy and being overwhelmed by the demands of diabetes.

Results from a more extensive study demonstrated 67.1% of 255 adolescents with T1DM reported using multiple daily injections versus insulin pumps, which differs from this study population (Lasaite et al., 2016). Another systematic review revealed most adolescents with T1DM reported no relationship to the level of diabetes distress regarding insulin modality (Hagger et al., 2016). These studies were limited in that they were non-randomized and included small sample sizes. Regardless of insulin modality, this study's findings are consistent with other studies reporting the existence of diabetes distress among adolescents, yet no significant differences regarding insulin modality.

Diabetes Distress and Glucose Monitoring

Continuous glucose monitoring (CGM) allows individuals with diabetes to wear a continuous glucose monitoring device rather than multiple daily finger sticks to check blood glucose. CGM has been associated with lower levels of diabetes distress among adolescents with type 1 diabetes mellitus (Vesco et al., 2018). This study compared those participants using CGM versus glucometers, which most participants reported using CGM technology (92.6%). The comparison test was not conducted based on these limited records; therefore, knowledge of whether there is a relationship of glucose modality with the level of diabetes distress is unknown in this study. Study participants reported minimal distress regarding feeling they were not testing blood sugars frequently enough, which supports most participants using CGM technology. This finding presumes that using CGM technology aids in reducing distress associated with day-to-day management in adolescents with T1DM. A systematic review described three studies of which there was no correlation of diabetes distress relative to glucose monitoring frequency, although specific evaluation of glucometer use versus continuous glucose monitoring was unclear (Hagger et al., 2016).

Diabetes Distress and Diabetes Duration

Diagnosis duration among the study participants averaged 15.22 years, ranging from less than 1 to 12 years. The most significant frequency of time included an average of 5 years. There was even cumulative distribution of diagnosis duration among participants divided as diagnoses less than 5 years and longer than 5 years. This division allowed for good distribution of diagnosis duration when comparing overall diabetes distress relationships. This study revealed no statistical significance among all survey participants' level of diabetes distress relative to the duration of diagnosis. Limited evidence exists comparing the duration of diabetes diagnosis and diabetes distress levels among adolescents with T1DM. Therefore, the findings of this study, combined with limited other studies, suggest that diabetes distress in relation to diabetes duration includes future prospective studies to evaluate an association (Hagger et al., 2016).

Diabetes Distress Screening in Adolescents

The study's scores using the DDS as a screening tool indicated 39% of all participants ages 13 through 17 years reported minimal diabetes distress, 36% reported moderate distress, and 25% reported significant levels of diabetes distress. The difference among participants reporting minimal distress to moderate distress differed by only one participant. Combined results of moderate and significant diabetes distress among all participants included an overwhelming 61%. These findings indicated that most adolescents with T1DM completing the study have diabetes distress that warrants further evaluation and assistance to improve future health outcomes. Type 1 diabetes mellitus is one of the most common chronic conditions among adolescents, with peak occurrences around puberty (Kraaij & Garnefski, 2015). The DDS in this study provided valuable information regarding the prevalence of diabetes distress among patients in the endocrinology clinic, which previously was unknown. Based on this study's findings, the

DDS appears to be an appropriate tool for screening adolescent diabetes distress, although further studies using this tool are necessary.

There are limited screening tools aimed at evaluating diabetes distress among adolescents. The Diabetes MILES (Management and Impact for Long-term Empowerment and Success) Youth Study conducted in Australia used the PAID-T scale adapted from the adult PAID scale to evaluate diabetes distress in 450 adolescents with T1DM (Hagger et al., 2017). Among Australian adolescents ages 13 to 19 years of age, results indicated a higher prevalence of significant diabetes distress (36%) than those reporting moderate-to-severe distress (21%). The D1Now study in Ireland is currently under development. It aims to use the DDS, which was used in this study, to determine the prevalence of diabetes distress among adolescents with T1DM for developing (Morrissey et al., 2020).

Study Limitations

This research study's limitations included the generalizability of the results based on the small sample size and ability to capture diabetes distress. The study mainly involved females (71.43%) and White (92.86%) adolescents, limiting evidence in males and other ethnic backgrounds. Another limitation included the relatively short 8-week duration of the descriptive research in identifying the prevalence of diabetes distress in adolescents with type 1 diabetes mellitus. A longer study duration would allow for increased sample size, including those with more varying demographics.

There were also unpredicted limitations, including reduced interest in study participation along with incidents of those deciding not to complete the survey within the study timeframe. The REDcap survey did not confirm receipt of the emailed survey links, yet one participant email invitation returned undeliverable. It is also unknown if emailed survey links were automatically sent to participants' spam folders and not received. Secondary approval from the Carilion IRB was received to generate end-of-study reminder emails to participants to complete the study by the end of the 8-week duration. Although the study aimed at identifying diabetes distress among adolescents, a larger sample size may have been obtained if all individuals with T1DM were eligible, regardless of age. A survey tool aimed at younger children, though, is currently unknown.

CONCLUSION

Management of type 1 diabetes involves complex and regimented care to reduce the development of associated complications. Complications associated with poorly controlled diabetes include both physical and psychological problems, many of which are preventable. Depression and diabetes distress are often overlooked psychological complications linked with poor self-care behaviors leading to physical complications, which may be irreversible, including vision and kidney damage (Holt et al., 2014). Adolescents are at increased risk for depression, even without underlying chronic medical conditions such as diabetes (VDH, 2017-2018). (Virginia Department of Health [VDH], 2017-2018) Additionally, adolescents with T1DM report high rates of diabetes distress, which is a precursor to depression and, if unidentified or overlooked, leads to suboptimal diabetes outcomes (Hagger et al., 2016).

Study findings provided valuable information regarding the prevalence of diabetes distress among adolescents with T1DM in receiving care in a pediatric endocrinology clinic in Southwest Virginia, which currently has not been the routine standard of care. These findings support the implication that diabetes distress is reported among most adolescents, and therefore warrants the development of prevention programs and routine screening as a change in practice. Based on the 66% response rate for this study, an online survey tool appears to be a favorable application for adolescents already knowledgeable of Internet technology. The personal nature of the diabetes distress scale may be more receptive to adolescents as an online format rather than face-to-face interaction (Hagger et al., 2016).

Based on the study findings, the Diabetes Distress Scale appears to be an appropriate tool in identifying diabetes distress concerns among adolescents. Through routine evaluation of diabetes distress, efforts at reducing distress can be made, leading to long-term outcomes of improved HbA1c, reduction in diabetic ketoacidosis hospitalization rates, and medical costs. Additional studies for identifying effective interventions are necessary for reviewing these long-term effects. The study offers support for more extensive research conducted over a more extended period to determine whether a change in practice as a standard of care in addressing diabetes distress should become routine in the pediatric endocrinology clinic

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APPENDIX A

DDS (DIABETES DISTRESS SCALE) DDS1.1
DDS 12.1.17 © Behavioral Diabetes Institute

DIRECTIONS: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number. Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1". If it is very bothersome to you, you might circle "6".
1-Not a Problem, 2- A Slight Problem, 3 – A Moderate Problem, 4 – Somewhat Serious Problem, 5 – A Serious Problem, 6 – A Very Serious Problem

1. Feeling that diabetes is taking up too much of my mental and physical energy every day.
1 2 3 4 5 6
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.
1 2 3 4 5 6
3. Not feeling confident in my day-to-day ability to manage diabetes.
1 2 3 4 5 6
4. Feeling angry, scared and/or depressed when I think about living with diabetes.
1 2 3 4 5 6
5. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.
1 2 3 4 5 6
6. Feeling that I am not testing my blood sugars frequently enough. 1 2 3 4 5 6
7. Feeling that I will end up with serious long-term complications, no matter what I do.
1 2 3 4 5 6
8. Feeling that I am often failing with my diabetes routine.
1 2 3 4 5 6
9. Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).
1 2 3 4 5 6
10. Feeling that diabetes controls my life. 1 2 3 4 5 6
11. Feeling that my doctor doesn't take my concerns seriously enough.
1 2 3 4 5 6
12. Feeling that I am not sticking closely enough to a good meal plan.
1 2 3 4 5 6
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.
1 2 3 4 5 6
14. Feeling overwhelmed by the demands of living with diabetes. 1 2 3 4 5 6
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes.
1 2 3 4 5 6

16. Not feeling motivated to keep up my diabetes self-management. 1 2 3 4 5 6
17. Feeling that friends or family don’t give me the emotional support that I would like.
1 2 3 4 5 6

APPENDIX B

DDS1.1 SCORING SHEET

INSTRUCTIONS FOR SCORING:

The DDS17 yields a total diabetes distress score plus 4 subscale scores, each addressing a different kind of distress. To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale.
Current research1 suggests that a mean item score 2.0 – 2.9 should be considered 'moderate distress', and a mean item score > 3.0 should be considered 'high distress.' Current research2 also indicates that associations between DDS scores and behavioral management and biological variables (e.g., A1C) occur with DDS scores of > 2.0. Clinicians may consider moderate or high distress worthy of clinical attention, depending on the clinical context. We also suggest reviewing the patient's responses across all items, regardless of mean item scores.

It may be helpful to inquire further or to begin a conversation about any single item scored > 3.

Total DDS Score: a. Sum of 17 item scores. ______________
b. Divide by: _____17_______
c. Mean item score: ______________
Moderate distress or greater? (mean item score > 2) yes__ no__

A. Emotional Burden: a. Sum of 5 items (1, 4, 7, 10, 14) _______________
b. Divide by: _______5_______
c. Mean item score: ______________
Moderate distress or greater? (mean item score > 2) yes__ no__

B. Physician Distress: a. Sum of 4 items (2, 5, 11, 15) ______________
b. Divide by: _______4______
c. Mean item score: ______________
Moderate distress or greater? (mean item score > 2) yes__ no__

C. Regimen Distress: a. Sum of 5 items (6, 8, 3, 12, 16) ______________
b. Divide by: _______5______
c. Mean item score: ______________
Moderate distress or greater? (mean item score > 2) yes__ no__

D. Interpersonal Distress: a. Sum of 3 items (9, 13, 17) ______________
b. Divide by: _______3______
c. Mean item score: ______________
Moderate distress or greater? (mean item score > 2) yes__ no__

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