INPATIENT DIABETES DISTRESS SCREENING AND EDUCATION

A Thesis
by
KIRSTEN HERING

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Abstract
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Diabetes distress is stress experienced from the burden of managing diabetes. This thesis took the form of a quality improvement project to improve assessment and intervention of diabetes distress for inpatients with diabetes at Duke University Hospital to answer the following questions: What is the prevalence of diabetes distress on selected general medicine and cardiology units in Duke University Hospital? What is the severity of diabetes distress in people with positive screens in this setting? Is an educational diabetes distress intervention using hospital resources effective at reducing diabetes distress? Is the screening, assessment, and intervention for diabetes distress feasible in the inpatient setting? The analysis used a pre and post educational intervention design with description analysis of patient/nurse feedback. The Diabetes Distress Screening tools assessed the prevalence and severity of diabetes distress, and the patient/nurse feedback described the intervention's effectiveness and feasibility. Of the 33 patients screened for diabetes distress, 18 (54%) scored positive for distress. Intervention participants (n = 12) reported moderate to high levels of all four subscales of diabetes distress with notably high levels of emotional burden and regimen-related distress. Participants reported that the educational intervention was helpful and meaningful. Nurses (n = 3) identified time and nursing workload as barriers to implementing the screening. Diabetes distress

assessment and general education on coping skills, and peer support resources, can be incorporated into standard diabetes care. Quality improvement efforts should focus on automating the diabetes distress screening into existing nursing assessments and tailoring diabetes distress education with existing educational materials for inpatients.

Keywords: diabetes, diabetes distress, screening, inpatient, quality improvement, education

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INPATIENT DIABETES DISTRESS SCREENING AND EDUCATION

Chapter 1: Introduction

Background

People managing a chronic disease, like diabetes, often endure a life-long struggle to assimilate constantly changing treatment regimens and lifestyle recommendations into their daily lives. This adds another layer of tasks, responsibilities, and stress to manage for people living with diabetes. Diabetes distress is the expected emotional stress that is directly related to the burden of managing diabetes (Skinner et al., 2020). This term was first coined in 1995 by a group of psychologists and psychiatrists from the Joslin Diabetes Centre (Skinner et al., 2020). Symptoms of diabetes distress can include feeling overwhelmed or guilty about self-management, a lack of motivation to make changes, dissatisfaction with the provider or treatment plan, anxiety about short term and long-term complications, and not feeling supported (Fisher, Polonsky, & Hessler, 2019). Research has shown diabetes distress affects around 40% of people with type 1 and type 2 diabetes (Skinner et al., 2020). Without intervention, diabetes distress can become chronic and intensify (Fisher, Polonsky, & Hessler, 2019). Those with unaddressed diabetes distress are at a higher risk to develop complications from their diabetes (Hessler et al., 2017). Diabetes distress is linked to poorer glycemic control and self-management, which over time causes physical complications, such as diabetic ketoacidosis, neuropathy, nephropathy, and other micro and macrovascular disorders (Fisher et al., 2013; Peimani et al., 2022).

A newly recognized psychological complication of diabetes distress is diabetes burnout. Abdoli et al. (2021) first suggested diabetes burnout can arise from unresolved diabetes distress or arise on its own and advocated for addressing diabetes distress early to

prevent its progression into burnout. Diabetes burnout is characterized by apathy and withdrawal from diabetes self-management (Abdoli et al., 2020). Interviews of patients with diabetes revealed that diabetes burnout is more intense and episodic than diabetes distress, which is more akin to day-to-day worries related to diabetes (Abdoli et al., 2020). Diabetes burnout is also more closely linked to a decrease or cessation in self-care practices, leading to poorer outcomes such as higher hemoglobin A1c and less time spent in the 70-180 mg/dL range (Abdoli et al., 2020, 2021).

Significance

Patients who are experiencing diabetes distress and diabetes burnout are often labeled as noncompliant due to their poor self-management, but this label implies that they are willfully not following the advice of healthcare professionals regarding their care (Abdoli et al., 2020). This harmful perception may be due to healthcare professionals not recognizing diabetes distress in their patients and can impair the patient-provider relationship (Skinner et al., 2020). Diabetes distress screening and management continues to be absent from standard practice, despite being a recognized concept for over 20 years and being recommended by several prominent organizations (Skinner et al., 2020; Yared et al., 2020). Addressing diabetes distress can improve the person's ability to participate in self-management of their diabetes, potentially reducing the occurrence of both physical and psychological complications (Fisher, Polonsky, & Hessler, 2019; Abdoli et al., 2021). If healthcare professionals acknowledge and take actions to help the patients navigate the stressors causing the diabetes distress, then patient outcomes may improve (Adboli et al., 2020, 2021).

Purpose

This thesis took the form of a quality improvement project. The purpose of the quality improvement project was to improve assessment of and intervention for people with diabetes distress at Duke University Hospital. The research questions guiding this project were:

1. What is the prevalence of diabetes distress on selected general medicine and cardiology units in Duke University Hospital?

2. What is the severity of diabetes distress in people with positive screens in this setting?

3. Is an educational diabetes distress intervention using hospital resources effective at reducing diabetes distress?

4. Is the screening, assessment, and intervention for diabetes distress feasible in the inpatient setting?

Theoretical Framework

Nursing theories are particularly focused on holistic, person-centered care, rather than medical management of disease. Healthcare provider-patient interactions focused solely on medical management while ignoring psychosocial issues have been cited as a source of frustration and a contributor to diabetes distress (Fisher, Polonsky, & Hessler, 2019). Roy's adaptation model (RAM) is a grand nursing theory that has been the framework for many middle-range theories; one such middle-range theory derived from this model is Whittemore and Roy's (2002) adapting to diabetes mellitus theory. This theory uses the RAM framework to deepen understanding of diabetes as a chronic illness within the adaptive system (Whittemore & Roy, 2002). The adapting to diabetes mellitus theory views stabilization of the disease process and prevention of complications as the goal of physiologic adaptation.

Integrating diabetes and its management into one's life is considered the goal of psychosocial adaptation, rather than medical adherence, conveying the importance of the personal experience of living with and managing diabetes (Whittemore & Roy, 2002). Integrating diabetes into one's perception of self, their day-to-day life, and social relationships represents the RAM goals of self-concept, role-function, and interdependence adaptation. Health-within-illness is the overarching goal of adapting to diabetes as this means that stabilization and integration are both occurring, and the person is reaching their health potential (Whittemore & Roy, 2002).

The adapting to diabetes mellitus theory states that diabetes management could be a focal, contextual, or residual stimulus, which applies well to diabetes distress occurring and recurring throughout the person's life and stage of diabetes (Whittemore & Roy, 2002). A significant event, such as a diabetes complication or hospitalization, that brings on diabetes distress is considered a focal stimulus. Diabetes distress can also be triggered by the context of another stimulus, like a change in financial situation, or a residual stimulus, such as recurrent failure to meet health goals. The adapting to diabetes mellitus theory emphasizes the importance of psychosocial aspects of chronic illness which had been lacking in diabetes medical management and has led to diabetes distress not being appropriately addressed. Diabetes distress, within the context of this theory, is viewed as an ineffective coping response to a stimulus, particularly within the process of integration. The stimulus could be a change in medication regimen, exhaustion, lack of support, or not experiencing stabilization of diabetes despite self-management strategies. Within this theoretical framework, the interventions would be focused on improving the integration of diabetes into the person's life by acknowledging the stimuli and the response, setting a goal and intervention to improve

adaptation and integration, and then evaluating the change (Whetsell et al., 2018). This aligns with the recommendations proposed by Fisher, Polonsky, & Hessler (2019) which are to assess for diabetes distress, discuss feelings, beliefs, and expectations, help patient adjust perspectives, develop a plan, and follow up on the plan.

One limitation to using this middle-range theory is that there has not been much research testing the strength of its concepts. However, the authors of this theory continued to develop it by creating a study which focused on integration-based nurse coaching sessions and interviewing participants about the challenges of integration under this framework (Whittemore et al., 2002). The results determined that finding a balance in the integration of diabetes and life would resolve negative feelings and improve satisfaction, which should decrease a person's risk for diabetes distress.

As I planned for the thesis project to include adults, I used Knowles' adult learning theory to frame the educational intervention (Candela, 2020). Adult learners are motivated to learn when the educational content has a clear application and relevance to their lives (Candela, 2020). Adults particularly prefer problem centered learning and desire to be an active participant in the learning process (Candela, 2020). Adult experiences directly affect their learning styles and receipt of information, as well as serving as a resource to draw upon. Reflection is crucial for adult learners to synthesize the new information with their life experiences and to make sense of the concepts and their application (Candela, 2020). These principles of the adult learning theory support the focus and intentions of the diabetes distress educational intervention that was part of this quality improvement project. To engage patients in learning, they were asked to complete a two-question tool to determine their personal level of diabetes distress. This created the meaningful and problem centered basis

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for their participation in the diabetes distress education. The patients were then asked to reflect on their experiences with diabetes to determine how to apply diabetes distress management in their own lives. The format of the education also allowed for the patients to self-direct their learning in both the selection of resources for self-study and the pace of the guided discussion (Candela, 2020).

Summary

The management of the psychological toll of diabetes, specifically diabetes distress, has long been overlooked by healthcare providers, and patients are experiencing the consequences (Fisher, Polonsky, & Hessler, 2019). Instead of receiving the help they need, they are often labeled as non-compliant or resistant to treatment regimens due to their anxiety and difficulty self-managing their disease (Abdoli et al., 2020). Under the framework of the adapting to diabetes mellitus theory, diabetes distress can be triggered by an acute focal stimulus or a chronic residual stimulus, which can take the form of hospitalization due to developing an acute complication or exacerbation of chronic complications of diabetes (Whittemore & Roy, 2002). With this in mind and a lack of research studies utilizing the hospital setting, this quality improvement project implemented the recommended screening and an educational intervention in the inpatient setting to understand and address diabetes distress in this overlooked population. Whittemore and Roy's (2002) adapting to diabetes mellitus theory was used as a framework for organizing the content of the diabetes distress education. Knowles' adult learning theory guided the design of the intervention for patients experiencing diabetes distress in order to support for a clearer understanding of the diabetes distress concept and its management (Candela, 2020).

Chapter 2: Literature Review

Introduction

A literature review was done to find recommendations and insights of researchers specializing in diabetes distress. There are several prominent researchers who spearheaded the exploration of diabetes distress to provide relevant content pertaining to the concept, measurement, and treatment of diabetes distress. Their evidence-based measurement tools and treatment recommendations informed the quality improvement project design and educational intervention content.

Review of the Literature

Diabetes Distress

Hessler et al. (2017) executed a prospective study that measured participants' HbA1c, diabetes distress, depression, and missed insulin doses at baseline and at 9 months. The results showed a correlation between higher levels of diabetes distress and a higher HbA1c, as well as a higher number of missed insulin doses. This study helped establish evidence supporting the importance of addressing diabetes distress related to the physical measures of diabetes management. It also further delineated diabetes distress as its own concept by showing a lack of correlation between depression and diabetes outcomes.

Skinner et al. (2020) presented a comprehensive summary of the current research and practices surrounding diabetes distress. They discussed the prevalence, etiology, assessment, current management strategies, and gaps in research and practice. Analysis of relevant studies revealed the prevalence of diabetes distress is often higher in women, young people, those with a shorter diabetes duration, a lack of social support, and non-white ethnic groups (Skinner et al., 2020). The etiology of diabetes distress is of course derived from the

experience of living with diabetes; however, Skinner et al. (2020) made a point of discussing the link of poor provider communication to the development of diabetes distress. Poor communication was described as failure to address patient concerns, use of medical jargon instead of plain language, attempting to motivate through the threat of complications, and limited patient-centered problem solving and goal setting (Skinner et al., 2020). As a synthesis of the existing research, this review cohesively highlighted the assessment and management of diabetes distress using many primary sources that are discussed later in this literature review.

Measurement of Diabetes Distress

Polonsky et al. (2005) were not the first group of researchers to develop a validated screening tool for recognizing diabetes distress but sought to improve upon the existing ones. The Diabetes Distress Scale (DDS-17) was conceptualized by patients with diabetes and healthcare professionals reviewing the currently available scales and providing feedback to narrow the concepts and clarify the scale items. A unique aspect of the DDS-17 compared to other screening tools is that it contains subscales: emotional burden, physician-related distress, regimen-related distress, and diabetes-related interpersonal distress. The addition of these subscales can help providers target interventions to the areas where the patient is experiencing distress (Polonsky et al., 2005).

Fisher et al. (2008) analyzed the DDS and its 17 items with the goal of finding up to four items that validly reflect diabetes distress to save time in screening patients. The researchers ultimately narrowed the DDS-17 to two items that included the subscale categories of emotional burden and regimen-related distress, thus creating the DDS-2. It is recommended is to screen patients with the DDS-2 initially; then any patient who screens

positively should take the DDS-17 to provide a better understanding of their diabetes distress experience and appropriate interventions to implement (Fisher et al., 2008). The screening process used within this quality improvement project followed this recommendation.

Treatment of Diabetes Distress

Reducing Distress and Enhancing Effective Management (REDEEM), a comparative, pragmatic randomized study performed by Fisher et al. (2013), provided some of the foundational data concerning interventions to reduce diabetes distress. Three types of educational interventions with interval check-ins were implemented and compared for their effectiveness. One intervention was minimal with diabetes-related health risk information, another used self-management education with goal setting, and the third used the same self-management education with goal setting but added diabetes distress focused education. The results showed significant decreases in diabetes distress in all three intervention groups, which indicates that perhaps simply engaging with the participants about their diabetes management and diabetes distress helped empower them to overcome the distress themselves. However, those with higher levels of diabetes distress or specifically regimen-related distress did not benefit as much from self-management education alone, suggesting that they may require diabetes distress specific education.

Peimani et al. (2022) demonstrated that a simple change in how we interact with patients can have a positive effect in reducing diabetes distress. Study participants filled out a survey to record occurrences of different aspects of patient-centered communications within the past 12 months as well as the DDS-17. These aspects of patient-centered communication, which mirror the aspects of poor communication noted by Skinner et al. (2020), were Hurried Communication, Elicited Concerns/Responses, Explained Results/Medications, Patient-

centered Decision-making, and Compassionate/Respectful communication (Peimani et al., 2022). The survey results demonstrated low occurrences of Hurried Communication and high occurrences of all the other aspects were associated with lower levels of diabetes distress. They also looked at any effects of patient-centered communication on the relationship between insulin use and diabetes distress since insulin use has been linked to higher levels of diabetes distress. Higher occurrences of Explained Results/Medications and Patient-centered Decision-making and lower occurrences of Hurried Communication were shown to moderate the relationship between insulin use and level of diabetes distress. The guided discussion utilized in this project encompassed all these aspects of patient-centered communication to improve its impact on the participants' diabetes distress.

Shifting focus to more psychologically based interventions, Fisher, Hessler et al. (2019) noted the significance of the relationship between emotional regulation, cognitive skills, and diabetes distress. Study participants were placed into intervention groups to compare a focus on emotional regulation and cognitive skills versus diabetes distress specific education. While diabetes distress levels improved in both groups, this study's findings reinforced the hypothesis from the REDEEM results that basic education and discussion about the participants' emotions and cognitive skills related to diabetes management may be just as effective as diabetes distress specific education in reducing diabetes distress (Fisher et al., 2013; Fisher, Hessler et al., 2019). These studies indicate that it does not take a complicated intervention to set the patient up for success.

Schmidt et al. (2018) performed a systematic review of randomized controlled trials using psychological interventions to reduce diabetes distress. Only nine studies were included in this review, highlighting that there are very few studies that have measured

diabetes distress as a primary outcome and even fewer that have done so in a randomized controlled trial. The psychological interventions included mindfulness-based strategies, cognitive behavioral therapy, a combination of the two, and motivational interviewing. In eight of these studies, all interventions, including purely educational ones and psychological ones, were effective in reducing diabetes distress (Schmidt et al., 2018). One common feature of these studies was the length of the intervention and follow up, usually lasting weeks or months. This again supports the idea that the intervention itself may be less important than the engagement with the patient regarding their diabetes distress and self-management.

Mathiesen et al. (2019) performed a systematic review of research studies that included diabetes distress as a primary or secondary outcome measure. Unfortunately, the review only revealed low to moderate evidence to support the studies' various psychosocial interventions implemented for vulnerable patients with type 2 diabetes. However, the findings did support more intensive versus brief interventions, which could be carried out either through individual or group sessions involving emotional regulation and educational materials. The low quality of evidence shows a continued need for further research; however, the data found in this systematic review remains consistent with previous studies or systematic reviews and can be used to guide practice until the most effective level of intensity, time frame, set-up, material, and follow-up can be determined more definitively.

Fisher, Polonsky, & Hessler (2019) detailed steps that healthcare professionals can implement to include diabetes distress in their routine care. Results from their own research trials and protocols were used as the foundational evidence for their recommendations, displaying direct application of evidence-based practice. Their five-step implementation plan can easily be modified to inform any level of healthcare provider how to effectively use

conversation strategies to improve patient education and interactions as an intervention for diabetes distress (Fisher, Polonsky, & Hessler, 2019). As previously discussed in relation to the adapting to diabetes mellitus theory, diabetes distress can develop simply from the unrelenting burden of managing diabetes day-to-day or develop and intensify in response to a specific stressor like a new complication or change in regimen (Fisher, Polonsky, & Hessler, 2019). Therefore, the first recommendation in their plan is adding diabetes distress assessment and education into all patient encounters and into stressful situations with "critical diabetes events" (Fisher, Polonsky, & Hessler, 2019, p. 801). The next steps are to discuss the patient's feelings and expectations through active exploration, acknowledgement and labelling of feelings, summarizing, reflecting, and normalizing and to reframe their perspectives to remove distortions and unrealistic expectations of their self-management (Fisher, Polonsky, & Hessler, 2019). A conversation using this model may be sufficient for some patients, but for those who need further assistance the provider should help them create a plan to improve their coping skills and manage their negative feelings when they arise. Once a goal is set, the healthcare provider should follow-up with the patient on their progress and coping in two-week intervals via phone or in-person (Fisher, Polonsky, & Hessler, 2019). Alongside this implementation plan, Fisher, Polonsky, & Hessler (2019) noted that while reduction of diabetes distress can allow for improvement in self-management behaviors, it does not necessarily directly improve diabetes outcomes. Therefore, outcome measures for a diabetes distress intervention should assess the levels of distress and self-management behaviors, not clinical measures of diabetes management.

Current Practice

Researching what diabetes distress is and how to manage it is only effective if healthcare practitioners are using this knowledge in their practice, which Yared et al. (2020) asked of diabetes specialists in community care settings. A self-reported survey designed by these researchers revealed a majority of the endocrinologists and diabetes educators only used a diabetes distress scale 0-25% of the time during their patient encounters. The participants noted that barriers to incorporating diabetes distress screening into their practice included lack of time and uncertainty.

McGrath et al. (2021) sought similar information through a qualitative evidence synthesis. The studies included in this synthesis also recognized barriers of lack of time and uncertainty in skills needed to perform the screening or provide follow up care. Other barriers noted were providers having poor awareness of the rationale for screening, prioritizing physical aspects of diabetes care, and language or cultural barriers. Based on these findings, McGrath et al. (2021) recommended educating providers on the rationale for screening, emphasizing the benefits of screening, ensuring access to resources to manage diabetes distress, or incorporating collaborative interprofessional care. Finding ways to overcome these barriers and implement these recommendations within the hospital setting or the community setting will be a crucial aspect of beginning diabetes distress management.

Summary

Despite the research and recommendations on how to define, measure, and treat diabetes distress, this information has not been assimilated into healthcare practice, as evidenced by Yared et al. (2020) and McGrath et al. (2021). After reviewing the literature, there was no study based within a hospital-setting, despite the high number of patients with

diabetes coming through the hospital system who could be triggered into diabetes distress by a new diagnosis, change in treatment regimen, or exacerbation of complications from diabetes. To begin to recognize and assist this patient population, increasing awareness of diabetes distress for healthcare providers for their patients with diabetes (PWD) by implementing a standard practice of screening for diabetes distress and education can improve care for patients with diabetes. For this quality improvement project, the five-step implementation plan proposed by Fisher, Polonsky, & Hessler (2019) informed the design and content of the educational intervention and its evaluation plan.

Chapter 3: Project Implementation

Project Design

This quality improvement project utilized a quasi-experimental, descriptive, and pre and post intervention evaluation design. The quasi-experimental design allowed for the purposeful sampling of PWDs who screened positive for diabetes distress to participate in the intervention and did not require randomization of the participants or the presence of a control group (Stratton, 2019). The descriptive approach enabled gathering of data to answer the research questions about prevalence of diabetes distress on the selected inpatient units, the severity of diabetes distress in those screening positive, and the feasibility and value of the intervention. The pre and post intervention evaluation was chosen for the purpose of evaluating the effectiveness of the educational intervention by comparing the diabetes distress levels prior to the intervention and during the follow-up after the intervention.

Ethical Considerations

The institutional review board representing Appalachian State University approved this thesis as a quality improvement project under study number HS-22-32. The institutional review board representing Duke University Hospital approved this quality improvement project under protocol ID Pro00111328. There were no foreseeable risks to the patients participating in this project outside of discomfort due to sharing personal details and the collection of their demographic information. Participants received informed consent documentation detailing the purpose and content of the screening and intervention, what and how personal information would be used, any foreseeable risks to them, how their personal information would be stored securely, and contact information for the research team. Verbal

consent was obtained from each participant prior to proceeding with the intervention and follow-up.

Setting

This project was implemented on three inpatient units within Duke University Hospital, which serve general medicine and cardiology patient populations. These units were selected due to their high rates of admitting patients with diabetes (PWD). The average length of stay for patients on these units during the project timeframe was 9.6 days; however, due to the varied reasons for admission to these units, the length of stay often ranges from two days to several weeks. As a large academic medical center, these units care for patients who are often more ill or require different specialists than those found in a smaller hospital. Hospital leadership and unit management approval was obtained for the project activities to occur in these locations.

Sample

Patients with a medical history of diabetes mellitus admitted to three inpatient units during the 8-week timeframe of the project were the target population. Standard patients on these units are typically 50 to 80 years old and have several comorbidities. The inclusion criteria were being at least 18 years old, having an active medical history of diabetes mellitus of any type, and being able to independently engage in screening and the intervention. The exclusion criteria were having no active medical history of diabetes mellitus, altered mental status, and an inability to independently complete the screening or engage in the intervention. The intended sample size for this project was at least 30 PWDs with positive screens or a total of 60 PWDs screened for diabetes distress.

Measures

　　To screen for and measure patients' diabetes distress, this project utilized the DDS-2 and DDS-17 screening tools. The DDS-2 uses two statements to gauge the level of diabetes distress a person is experiencing. The statements are rated on a scale from 1 to 6 and relate to how much the person's life is affected by certain aspects of diabetes management; on this scale, 1 indicates "Not a Problem" and 6 "A Serious Problem" (Fisher et al., 2008). These two statements are "Feeling overwhelmed by the demand of living with diabetes" and "Feeling that I am often failing with my diabetes regimen" (Fisher et al., 2008). These statements were taken directly from the DDS-17, from which the DDS-2 was derived, and yielded scores with the strongest correlation to the DDS-17 total scores during development (Fisher et al., 2008). The cutoff points for a positive screen on the DDS-2 are the sum of the two items' scores being greater than/equal to 6 or the average of the item scores being greater than/equal to 3 (Fisher et al., 2008).

　　The DDS-17 (see Appendix A) includes 17 statements each rated using a scale from 1 to 6, 1 indicating "Not a Problem" and 6 "A Very Serious Problem" (Polonsky et al., 2005). The DDS-17 has four subscales: emotional burden, physician-related distress, regimen-related distress, and interpersonal distress (Polonsky et al., 2005). The overall distress score is achieved by calculating the mean of all 17 rated responses. Each subscale category has corresponding statements; the mean of these statements' scores determines the subscale's score (Polonsky et al., 2005). The DDS-17 cutoff points for the overall and subscale scores are as follows: little to no distress is a score of less than 2, moderate distress is a score of 2 – 2.9, and high distress is a score of 3 or greater (Fisher et al., 2012). Internal consistency of the overall scale and the subscales was established using Cronbach's alpha with resulting

values of 0.88 to 0.93 across the scales (Polonsky et al., 2005). Polonsky et al. (2005) established the validity of the DDS-17 using Pearson correlations to compare the scores with established screens for depression, self-management engagement, and metabolic variables.

The educational intervention included a guided discussion using the open-ended questions listed in Table 1. The PWDs' responses to these questions assisted in understanding the level of diabetes distress, their experiences with diabetes distress, how the educational materials may help reduce their distress, and goal setting to address coping and areas of distress. The guided discussion questions were designed for this project based on the recommendations by Fisher, Polonsky, & Hessler (2019). The post-intervention follow-up used similar discussion questions to assess the effectiveness of the educational intervention and the PWDs' perception of its helpfulness (Table 2).

Table 1

Intervention Guided Discussion Questions

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1. Your screening scores show moderate/high levels of distress in the _____ subscale/subscales. Do you feel that is accurate and how is this reflected in your life?

2. How has your diabetes distress affected your diabetes self-management?

3. Diabetes distress is often characterized by feelings of anxiety, frustration, and a sense of failing in diabetes self-management. How can you start to view your diabetes self-management in a positive way to reduce these feelings?

4. Based on the materials you were given and this discussion, what do you think your next steps should be to help you manage your diabetes distress and/or improve your self-management?

5. What other resources or content do you think would be helpful to seek out to continue reducing your distress and/or improving your self-management?

Table 2

Post-Intervention Follow-up Discussion Questions

1. Your re-screening scores show _____ levels of distress in the _____ subscale/subscales. What changes do you recognize in your levels of distress or ability to self-manage your diabetes since receiving the educational resources?

2. How have you begun to view your diabetes self-management in a different or positive way?

3. How have you implemented next steps to reduce your diabetes distress and/or improve your self-management?

4. How have the resources you were given been helpful/useful in improving your understanding of and reduction of diabetes distress?

The nurses within the Diabetes Champion program who assisted in the project were asked about their experiences using the DDS-2. Their responses to the questions in Table 3 were used to assess the feasibility of standardizing the process of screening and providing educational materials in the inpatient setting. The Diabetes Champions were asked to answer these questions at two-week intervals during the project timeframe.

Table 3

Diabetes Champion Questions

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1. How has the screening process gone for you so far?

2. How long would you estimate it takes for you to screen a patient using the DDS-2?

3. What potential or active barriers to unit-based implementation do you perceive at this time?

4. What would you change to improve the feasibility or effectiveness of this screening process?

5. Do you have any other thoughts or experiences related to this project/screening process you want to share?

Intervention

Following IRB approval, as the project lead, I provided training for the two nurse volunteers within Duke's Diabetes Champion program in the use of the DDS-2, how to access the project-specific educational resources, and document the patient information in a secure Duke Box document. The training included a recorded Zoom presentation utilizing the screenshare function to allow for visual step-by-step explanations and a written copy of expectations and instructions. The Diabetes Champions, whose usual role includes acting as a resource for PWDs and the nurses caring for PWDs, identified patients on their unit who met the inclusion criteria. We screened these PWDs using the DDS-2 and documented the responses in an Excel Spreadsheet in a secure Duke Box folder. Additional information gathered from the PWDs included their last name, room number, age, gender, race/ethnicity, and amount of time since initial diabetes diagnosis. If the patient screened negative, the nurse simply provided usual care including the standard educational resource documents related to diabetes management and diabetes distress. If the patient screened positive for distress on the

DDS-2, the nurses provided the standard educational documents and notified me of the positive score. The standard educational documents consisted of the Duke Diabetes Care Handbook, which details basic aspects of diabetes self-management, and an article about diabetes distress by the Association of Diabetes Care and Education Specialists (ADCES).

I monitored the Duke Box entries made by the Diabetes Champions and entered the data into a Duke Qualtrics survey to create numerical and visual representations of the demographic data obtained. Once notified of a positive screen, I approached the patient for further screening and participation in the intervention. After providing verbal informed consent to participate in this project, patients received a brief overview of the definition, common signs, and negative effects of diabetes distress in the form of a short verbal discussion and written documents. Next, the patient was screened for diabetes distress using the Diabetes Distress Scale (DDS-17) following Fisher et al. (2008) recommendations.

Specific recommendations for a diabetes distress intervention from Fisher, Polonsky, & Hessler (2019) include a person-centered conversation that involves exploration and normalization of the patient's emotions, prompts reflection, summarizes the discussion, shifts perspectives, and leads to a plan of action. Therefore, the educational intervention implemented in this project reflected these recommendations by providing patients with education focused on diabetes, diabetes distress, and their management, and a guided discussion on their specific sources of distress based on their screening subscale scores. So, after obtaining the patient's overall and subscale distress scores, a collection of written materials and short video links relating to general diabetes distress management and content specific to any elevated subscale scores were provided (Appendix B).

According to Herrman (2020), a guided discussion is the combination of several educational strategies to facilitate an interactive learning experience and prompt objective-driven discussion. Table 1 lists the questions designed for this guided discussion. The use of open-ended questions was intended to create a relaxed, conversational approach to the interaction to put the patient at ease. It also directly acknowledged the correlation of the resources' content and its application to the patient's personal life experiences, a key aspect of stimulating engagement according to the adult learning theory (Candela, 2020). Reflection allows the patient to contemplate the new educational content to improve understanding, attach personal meaning to it, and allow it to guide decision making (Bradshaw & Hultquist, 2021).

After completing the intervention, I obtained the contact information of the PWD and monitored their discharge from the hospital. Once the patient had been discharged for one to two weeks, I contacted them for the follow-up screening using the DDS-17 a second time and a discussion about the helpfulness of the educational intervention (see Table 2).

The educational resources provided to patients were procured from Duke approved websites and Duke's own existing educational resources, all of which had been evaluated and approved by Duke's Patient Education Governance Council prior to use. The education provided was selected to address each specific subscale in the DDS-17 (see Appendix B). Each positively screened patient received an additional article detailing general information about diabetes distress by the American Diabetes Association. For a positive emotional burden sub-score, written education discussing how to reframe perspectives of diabetes and yourself and healthy ways to cope were provided, as well as a video about how to stay motivated. For a positive physician-related distress sub-score, the written articles discussing

general information about diabetes distress provided the most content on how to improve discussions and bring awareness of distress to their providers. For a positive regimen-related distress sub-score, written material listing support resources for general diabetes management, nutrition, phone applications, fitness resources, and support groups and videos discussing how to maintain lifestyle changes, problem-solving, and how others manage diabetes were provided. For a positive interpersonal distress sub-score, written and video materials discussing peer support groups with ways to connect to existing groups were provided. However, each patient was asked if they wanted any of the other educational documents available, whether or not they scored positively for that sub-score, to allow them to engage in and self-direct their learning.

 The concepts of the Universal Design of Learning were applied to the format of this educational intervention (Boskic et al., 2008). Multiple means of representation were utilized by providing the patient educational content through various methods (Boskic et al., 2008). The use of written, audiovisual, and verbal educational methods was meant to accommodate the needs of visual and auditory learners. The written and audiovisual content was also provided to the learner in a way that could be reviewed multiple times and at their own pace. Each of the written materials was selected from a recognized organization or educational database to ensure that they were developed at an appropriate reading level for the general population. The concept of multiple means of engagement was also represented in this design by involving the learner directly through discussion and reflection and personalizing the education and discussion to increase meaning for the learner (Boskic et al., 2008).

Data Collection and Storage

DDS-2 screening scores and patient demographic information were collected from all screened PWDs by the Diabetes Champions and myself during the initial screening encounters. These data were documented in a secure Duke Box file, which is stored within the Duke Box cloud storage and not accessible by anyone other than the Diabetes Champions and me without direct invitation to the document. This information was also put into a Duke Qualtrics survey that only I had access to for data analysis.

The DDS-17 screening scores and notes from the PWDs' guided discussions were documented in a separate Duke Box spreadsheet with the patient's last name and contact information for follow-up. Only the Duke Research team, who were overseeing the project, and I had access to this file. I wrote the notes from the guided discussions, both during the intervention and follow-up, in real time to capture the highlights of the PWD's responses in the form of direct quotes and short phrases summarizing the response to each question.

The Diabetes Champions' responses to the check-in questions were obtained two weeks after their first completed screening and in two-week intervals subsequently. Their responses were collected via Duke email and stored in a Duke Box file with no identifying information. Once the project was complete and all the patients had been contacted for the post-intervention follow-up, the patient identification information of the last name and contact information was removed from the spreadsheet. The remaining de-identified patient health information will be stored in the Duke Box spreadsheet for six years following the completion of the project.

Data Analysis

The demographic information gathered from the PWDs, both negative and positive for distress, was compiled into descriptive statistics of each group to determine the mean, standard deviation, and percentages within age groups, racial/ethnic groups, gender, and years since diabetes diagnosis. Descriptive statistics were also used for the scores of the DDS-2 and DDS-17 screenings to improve understanding of the sources and extent of diabetes distress within the sample. The effectiveness of the educational intervention was intended to be evaluated objectively by analyzing the DDS-17 scores of the patients' pre- and post-intervention with a paired t-test.

Responses to the open-ended questions posed to the PWDs and the two Diabetes Champions provided some qualitative data helpful to determining whether the screening and implementation were overall feasible and valuable. The narrative notes taken during the conversations with the PWDs was grouped into categories to describe patient experiences with diabetes distress and perceived helpfulness of the intervention for the PWD. The reported experiences were selected based on the frequency in which they were described by the PWDs. If similar statements were made by 3 or more PWDs, these statements were included in the results. The quotes included in the results reflect the original wording of the participants.

Chapter 4: Results

At the end of the eight-week project timeframe, 33 PWDs were screened for diabetes distress using the DDS-2. Of these 33 PWDs, 15 screened negative and 18 screened positive for diabetes distress. Twelve of the 18 PWDs who screened positive agreed to participate in further screening with the DDS-17 and the educational intervention. The results reported include descriptive statistics of the demographics of the total sample and those screening positive and negative, descriptive statistics of the DDS-2 and DDS-17 responses and scores, a summary of the PWD guided discussion responses, and a summary of the Diabetes Champions' experiences.

Demographics

Total Sample

Table 4 details the demographic data of the total sample and those who screened positive and negative. Just over half of the 33 PWDs screened were women. The ages of the PWDs ranged from 22 to 90 with a majority falling between 50-60 or 70-80 years old. The majority of the PWDs identified as African American/Black, followed by Caucasian/White, then Hispanic/Latino. The time since their diagnosis of diabetes ranged from two months to 62 years with the largest percentage falling between 10-15 years.

Positive Screens

Of the 18 PWDs who screened positive, nearly all of them were women. As for race/ethnicity, a significant majority identified as African American/Black. While the age range in this group was between 22 and 89, 44% of them were between the ages of 50 and 69. The range of years since their diagnosis was 1 to 48 years with the majority reporting 10-20 years since their diagnosis.

Negative Screens

The 15 PWDs who screened negative for diabetes distress had some distinct differences from those who screened positive. The gender majority was reversed from the positive group. The race/ethnicity reporting revealed an almost even split between PWDs identifying as Caucasian/White or African American/Black. Their ages were more clustered with a majority being 50-60 or 70-80 years old. There was a wider array of diabetes durations which ranged from 1 month to 90 years since their diabetes diagnosis. No clear majority in relation to the years since diagnosis was noted amongst the negative screens.

Table 4

Demographics of Sample

Demographic	Positive Screens		Negative Screens		Total Sample	
	#	%	#	%	#	%
Gender						
Male	5	28	10	67	15	45
Female	13	72	5	33	18	55
Race/Ethnicity						
African American/Black	14	78	6	40	20	61
Caucasian/White	3	17	8	53	11	33
Hispanic/Latino	1	5	1	7	2	6

Demographic	Positive Screens			Negative Screens			Total Sample		
	M	SD	Range	M	SD	Range	M	SD	Range
Age (years)	51.7	17.9	22-81	64.2	13.1	39-90	57.1	16.8	22-90
Diabetes Duration (years)	15.3	12.3	1-48	14.2	18.8	0.08-62	14.9	14.9	0.08-62

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Screening Data

DDS-2 Responses

  Tables 5 and 6 detail the number of responses provided for each rating from one to six in the DDS-2 screenings by positive and negative screens respectively. Each DDS-2 patient screening took about 5-10 minutes, depending on how talkative the patient being screened was. The responses of the positive screens are relatively varied. Sixty-six percent of those who screened positive rated the severity of the first statement as either a 4 or 6. In response to the second statement, the ratings were more variable, spread across the ratings of 2 to 6. In contrast, an overwhelming majority of those who screened negative answered 1 "Not a Problem" in response to both DDS-2 statements.

Table 5

DDS-2 Positive Screens – Total Number of Responses Across the Rating Scale

	Not a Problem		Moderate Problem		Serious Problem	
	1	2	3	4	5	6
1. Feeling overwhelmed by the demand of living with diabetes	1	0	2	6	3	6
2. Feeling that I am often failing with my diabetes routine	0	1	4	5	5	3

Table 6

DDS-2 Negative Screens – Total Number of Responses Across the Rating Scale

	Not a Problem		Moderate Problem		Serious Problem	
	1	2	3	4	5	6
1. Feeling overwhelmed by the demand of living with diabetes	12	1	2	0	0	0
2. Feeling that I am often failing with my diabetes routine	12	1	2	0	0	0

DDS-17 Responses

All 12 of the PWDs who were positive using the DDS-2 and agreed to participate in the DDS-17 screen were positive for diabetes distress on this longer scale. Three of them had scores consistent with moderate levels of distress, and the other nine high levels of distress. Table 7 details the number of no distress, moderate distress, and high distress scores that occurred within each subscale of the DDS-17. The two subscales of emotional burden and regimen-related distress had a significant number of moderate to high level of distress scores. The subscales of physician-related distress and interpersonal distress had a more even spread of scores amongst the PWDs.

Table 7

DDS-17 Screening Subscales – Total Number of Scores Per Level of Distress

DDS-17 Subscale	< 2 = No Distress	2 = Moderate Distress	≥ 3 = High Distress
Emotional Burden	0	0	12
Physician-Related Distress	3	6	3
Regimen-Related Distress	0	2	10
Interpersonal Distress	4	2	6

Follow-Up DDS-17 Responses

Due to the sample goal not being met and the difficulty in contacting patients post-discharge, there were not enough patients available to be rescreened post-intervention to adequately evaluate the intervention using that method. Despite this, the pre-intervention DDS-17 scores were still compared descriptively with the corresponding follow-up DDS-17 scores post-intervention and discharge for the PWDs who completed both screens. Four of the 12 PWDs were able to be contacted after discharge to complete the DDS-17 to reassess

their levels of distress and inquire about their utilization of the educational resources. All four had a decrease in their total distress scores, three of which were significant enough to lower their overall distress score by a point. The one whose overall score did not change, relayed that he had not looked at the educational materials since he had been discharged. The PWD whose score decreased the most shared that she was taken off insulin a week after discharge, which greatly contributed to her reduction in diabetes distress. The other two PWDs had looked at the educational materials provided and had started to put some of their goals set during the guided discussion intervention into action at home.

Guided Discussion Responses

Regimen-related Distress

In the PWDs' responses to how diabetes distress was manifested in their lives, there were several recurring stressors discussed relating to regimen-related distress, which was one of the two highest scoring subscales (see Appendix C). Amongst all the PWDs, having to focus on their diet to manage their blood glucose and medication regimen was the most common distressing experience. They stated that it took a lot of effort and focus each day to make sure they were making the right choices with the food they have available, which for some was limited. Two other stressors were having to check blood glucoses frequently and the pain associated with it and administering insulin. One PWD stated that her fingers were numb and painful from her lancets, causing her to stop checking her blood glucose as often. This example may suggest that the pain involved in managing their diabetes is a deterrent to engaging in self-management. Another PWD expressed that he had a fear of needles and relied on others to help with checking his blood glucose and administering his insulin. Additional stressors discussed within the context of regimen-related distress were having to

be prepared to manage lows and having to manage other chronic illnesses on top of their diabetes.

Interpersonal Distress

Although only half of the PWDs had high levels of interpersonal distress, those that did discussed these stressors in more detail than the emotional burden or regimen-related distress concepts. A few of the PWDs were still in situations where they were caregivers or highly involved in the lives of their spouses, children, or grandchildren. Due to this, certain PWDs expressed that they prioritized taking care of others and put off caring for themselves, stating that it was "not their [loved ones'] burden to take care of [them]" or they are "worried about being a burden to someone else." Outside of caregiving, all the PWDs who had interpersonal distress expressed frustration with their friends or family not being supportive of their self-care efforts. Many of their family members made them "feel guilty for what [they] eat while making poor food choices in front of [them]." Another PWD stated "they don't have enough information to support me but don't take any information from me" regarding family members who had experience with type 2 diabetes but little with type 1 which the PWD had. On the other hand, one PWD also stated "no one seems to have time to help you, no one else wants to take on that other part of your life."

Emotional Burden

In response to how diabetes distress affected their self-management of diabetes, the emotional burden was the most discussed concept. The most frequent expressions were of feelings of exhaustion, defeat, and worry/fear. A few described how the fear of poor outcomes could act as a motivator in the short term, but often led to exhaustion and withdrawal from self-management over time. One PWD described their distress concerning

diabetes management as "depressing, it's all day, it never stops, and never have a day off." In response to this never-ending stressor, another PWD said she would "just throw up [her] hands and feel bad about it afterwards." Another recurring emotional burden stressor was the feeling that they are doing everything "right" but still having poor outcomes, like high or low blood glucose. Several gave statements describing the exhaustion and defeat: "It stopped me from functioning with it", "I'm tired of doing it", "Do I want to deal with it or how do I deal with it?", and "slows me down, not able to keep up with it."

Goal Setting

The next steps of the guided discussion were discussing ways for the PWD to have a more positive outlook on their diabetes self-management and setting goals to reduce their diabetes distress. These responses were more varied than the responses to the previous questions since they were intended to be personalized; however, seven of the PWDs set goals to seek out a peer support group or have a discussion with their family about their diabetes distress. Other goals included: learning more about diet and diabetes-friendly recipes, reviewing education on self-management in general, establishing an exercise routine, improving adherence to blood glucose checks and insulin administration, and engaging in positive self-talk.

Intervention Feedback

The educational interventions lasted an average of 45 minutes in their entirety, from obtaining informed verbal consent to the completion of the guided discussion. The direct feedback received about the educational materials and the guided discussion was positive. Most of the PWDs expressed they were grateful for the opportunity to simply talk about their struggles and diabetes distress. This was especially important as nearly all of the 33 total

PWDs screened had never heard of the term diabetes distress. Regarding the education specifically, the PWDs expressed an eagerness to look through the materials on their own time and felt that the materials included what they wanted to learn about or had resources they wanted to use. As I reviewed the education, the most requested education/resource outside of the ones specific to their elevated areas of distress were those relating to peer support groups.

Diabetes Champion Experiences

When initially recruiting nurses within the Diabetes Champion program to assist with this quality improvement project, six nurses expressed their interest in participating. By the time of project initiation, four of the six nurses continued to express their interest and availability to assist. I provided training that allowed the nurses to review the content on their own time and detailed the timeline and expectations for the project. Ultimately, only two of the four nurses completed any patient screenings. When prompted, the main barrier reported was finding the time outside of their regular shift duties to perform the screenings. Each of these nurses, and other nurses who asked about the project when they observed the screening process, recognized the value in pursuing this important aspect of diabetes care; however, the barrier of not having extra time to perform the screenings was too significant to overcome. The two Diabetes Champions who completed screenings also stated that they would have screened more if it was part of their workflow instead of an extra, optional task to complete. Other specific barriers to screening were working nightshifts as this shortened the patient availability for screening and having to precept a new graduate nurse during shifts.

Both Diabetes Champions also described positive interactions with patients while doing the screening and expressed surprise at how willing patients were to discuss their

diabetes with them. The training and resources provided to facilitate the screenings were reportedly easy to use and accessible. To improve the feasibility of implementing the screening process, they suggested creating a report in the electronic medical record to help quickly identify PWDs who can participate in screening or adding the screening questions to the admission assessment for PWDs.

Missing Data

PWDs (n = 6) were lost to the intervention due to discharge. For example, one of them was not feeling well enough to participate during three separate attempts to complete the screening before being discharged. In one instance, a patient screened positively using the DDS-2, but when I came to screen using the DDS-17 the patient exhibited an inability to engage in the screening conversation and intervention due to altered mental status. This patient's data was removed as they did not fully meet the inclusion criteria. Other missing data was the post-intervention DDS-17 and discussion with the 12 PWDs who participated in the intervention. Two of these PWDs provided numbers that were no longer active when contacted after discharge. The other six PWDs did not respond to any of the attempts to contact them via text, phone calls, and voicemails, though they had given verbal consent to be contacted after discharge during the inpatient intervention.

Chapter 5: Discussion

Demographics

The demographic data demonstrate that those who were screened were representative of the standard population of the General Medicine and Cardiology units used as settings for this project regarding the age ranges and percentages by race/ethnicity. The percentage of PWDs with positive screens was 54%. A true prevalence rate for diabetes distress on the project's selected units could not be calculated as not every PWD could be screened. It is possible that the prevalence rate in the inpatient setting, like the one used for this project, would be higher than the 40% prevalence reported for the general population, since PWDs who are hospitalized confront considerable stressors that could trigger diabetes distress.

The stark difference in gender and, to a lesser extent in race/ethnicity, between the positive and negative groups was in line with the trends for higher risk groups reported in Skinner et al. (2020). Despite having a higher percentage of African American/Black and women participants total, there was a clear divide that showed higher prevalence of distress in female PWDs and African American/Black PWDs and a conversely lower prevalence of distress in male PWDs and Caucasian/White PWDs. Another interesting demographic finding was the wide range of years since diagnosis of diabetes amongst those who were negative for distress. The lack of majority in a specific time frame in this group may indicate the presence of internal or social factors that aide in decreasing distress, especially since those with ample years of experience or knowledge (10-24 years since diagnosis) were shown to have higher levels of distress. This also signifies the need for continuing education and support for PWDs. Early in diagnosis, PWDs receive initial education and support along with a new motivation to learn to manage their diabetes. However, the motivation may wear

off over time and their lives and regimens often change, but no routine support or education is provided to these PWDs, leading to potentially higher prevalence of distress. One PWD even touched on this stating she hadn't "had a refresher course (in diabetes management) in 20 years." Collectively, in this sample those who were African American/Black, women, and ages 50-70 were most likely to exhibit diabetes distress. The number of PWDs positive for distress and these statistics of at-risk groups within the inpatient population emphasize the importance of screening in the hospital setting and setting up appropriate outpatient follow up.

There are still many relationships and trends to be researched to help us understand and identify at risk groups for diabetes distress; however, some recent studies are building a basis for this knowledge. Kamrul-Hasan et al. (2022) studied predictors of diabetes distress using patients with T2DM in outpatient endocrinology clinics in Bangladesh. From the 259 adults that participated, predictors of diabetes distress identified were insulin use, presence of any diabetes complication, residence in a rural area, and presence of major depression (Kamrul-Hasan et al., 2022). Noted predictors for no or low diabetes distress were being greater than 40 years old at the time of diabetes diagnosis and having a diabetes duration greater than 10 years. Dudley et al. (2022) conducted a study in the U.S. via an online survey recording participants demographic information and DDS-17 scores. This survey found higher prevalence of moderate to high distress in those who reported a longer diabetes duration than those with a short duration. Skinner et al. (2020) noted higher prevalence of diabetes distress in women, younger adults, those with lower social support, non-white ethnicity, and a shorter diabetes duration. Fisher, Polonsky, & Hessler (2019) reported higher rates in women, younger adults, those on insulin, those with poor glycemic control, a high

BMI, a longer diabetes duration, and presence of significant diabetes comorbidities. While my findings and each of these studies have similarities in regard to gender and race/ethnicity, there is no consensus on diabetes duration and risk for diabetes distress. Fisher, Polonsky, & Hessler (2019) recognized that rates of diabetes distress will vary across samples and settings, so healthcare providers should allow these known at risk groups to prompt close monitoring and action in addressing diabetes distress. However, screening and education should still be done for all PWDs to increase awareness and standardization of these practices.

Experiences of Diabetes Distress

The screening data collected depict characteristics and the levels of diabetes distress experienced by the sample. The most potentially interesting findings regarding the DDS-17 screens related to the subscale scores. The subscale for emotional burden was positive for high levels of distress amongst every PWD screened, regardless of whether their total distress score was moderate or high. Regimen-related distress was close behind with mostly high scores, then physician-related with mainly moderate scores, and interpersonal distress with either high or no distress scores. Kamrul-Hasan et al. (2022) also found similar differences in the levels of distress across the subscales. These findings can help inform providers as we improve our standard educational materials and resources offered to PWDs.

During the intervention, the participants discussed how diabetes distress was expressed in their lives and how it affected their self-management. The qualitative responses gathered from the PWDs support the current understanding of the phenomenon. The common experiences identified were feelings of exhaustion, defeat, and guilt. These experiences are consistent with recognized aspects of diabetes distress described by Fisher, Polonsky, &

Hessler (2019), specifically feeling overwhelmed or guilty about self-management, a lack of motivation to make changes, and not feeling supported. Another recognized characteristic of diabetes distress that was mentioned, but less frequently, in the guided discussions was anxiety about short-term complications, namely hypoglycemia, and potential long-term complications. The way PWDs described their experiences with diabetes distress also supported the distinction between distress and burnout made by Abdoli and colleagues (2021). One statement made in support of this was "it's all day, it never stops, and never have a day off."

An interesting aspect of these discussions was the amount of discussion surrounding the distress caused by lack of support from their families, even though it was not the most common source of distress. Those who scored high levels of distress in the interpersonal subscale spent the majority of the time during the guided discussion relaying the impact of their family interactions on their distress. The interactions described included criticism, guilt, lack of understanding or desire to learn, and unsupportive behavior. Leukel et al. (2022) researched the relationship and interactions between interpersonal emotional regulation, family involvement in diabetes management, and diabetes distress through self-report screenings. Interpersonal emotional regulation is defined as the act of relying on others outside of yourself to help manage negative emotions, meaning those with low interpersonal emotional regulation can manage their own emotions independent of outside sources. Based on the screening results, they found that having high interpersonal emotional regulation led to higher levels of diabetes distress (Leukel et al., 2022). Negative family involvement, much like the experiences described by the PWDs in this project, was also related to higher levels of diabetes distress (Leukel et al., 2022). Leukel et al. (2022) recommended targeting

reduction of negative family involvement and suggested that high use of interpersonal emotional regulation may be a risk factor for diabetes distress independent of the type of family involvement. Within the educational materials and during the guided discussion, the PWDs in this project were educated on ways to improve positive self-talk, seek peer support groups, and to initiate discussions with their family about negative interactions and practices as ways to reduce diabetes distress, all of which are consistent with these recommendations. Adding this to the fact that the peer support resources were seen as the most helpful new content to them, were requested by those who did not have interpersonal distress, and one of the main goals set was to seek a peer support group, shows a clear need for these types of resources and support to be made available for PWDs.

Effectiveness of Educational Intervention

Two PWDs were screened with the DDS-2 and DDS-17, participated in the educational intervention, reviewed the educational content after discharge, started working on the goals they set, and participated in the follow-up screening and discussion. Both PWDs had a decrease in their overall distress scores as the project intended. The barriers to follow-up should be further studied to improve the use of this evaluation method for the educational intervention.

During the guided discussions, I reviewed some of the educational materials (see Appendix B) with the PWDs. The PWDs expressed that the content targeted their areas of distress appropriately. The Duke Diabetes Care Handbook was helpful in addressing any self-management and diet-related questions. The most versatile resource was the list of resources and websites for nearly all the diabetes distress and self-management content areas. The articles about diabetes distress in general were both easy to review and use to highlight

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important points quickly. The two articles discussing peer support were also equally easy to review with some variance in content and resources to connect with peer support groups. The videos accessible by QR code were positively received by PWDs who had difficulty reading the articles or preferred audiovisual learning, but those with less technological ability were less interested in these resources.

In an effort to be thorough, the materials used were derived from several different sources and in different formats. However, this means the materials quickly added up to around seven different articles or papers the patient could review. Some patients requested resources outside of those within their elevated subscale content and these were provided to them. The resources could be further reviewed to ascertain the best ones addressing each subscale category to be used to reduce the cognitive load of the educational materials. Another recommendation is to incorporate content about diabetes distress and to address emotional burden and interpersonal distress into the Duke Diabetes Care Handbook. Regimen-related distress would already be addressed by its current content, so the addition of education on coping and resources for peer support would allow the Handbook to cover all the areas missing content.

Feasibility of Standardization

Regarding the quality improvement lessons from this project, the response from patients and nurses was positive at every stage. Several Diabetes Champions and nurses not participating in the project expressed that they recognized the value of the screening and intervention for diabetes distress. However, there remain barriers to gathering nursing engagement in the process. To compensate for the low nurse engagement, I also identified PWDs on the selected units and performed DDS-2 screenings. My screening encounters

averaged five minutes per patient, with negative screens taking less time, which could have been due to an increased familiarity with the DDS-2. The barriers reported by the Diabetes Champions were consistent with those of other healthcare providers listed by Yared et al. (2020) and McGrath et al. (2021), especially lack of available time to perform screening. One difference though was the Diabetes Champions had no uncertainty of how to screen or what to do with a positive screen due to the brief training provided at the start of the project. This suggests the education and training provided in this project on diabetes distress, use of the DDS-2, and the provision of the educational resources was sufficient and could be modified to effectively train other nurses to engage in these practices.

Since this was a voluntary project outside of their workflow, one way to address the lack of available time barrier would be to incorporate it into an existing standard assessment. One Diabetes Champion suggested adding the DDS-2 to the admission assessment for PWDs, which already includes screenings for suicidal ideation, alcohol withdrawal risk, and risk for falls. These screenings prompt a best practice advisory (BPA) when scored positively; for example, a patient whose screen indicates they are at risk for alcohol withdrawal has a BPA for the need for monitoring and possible pharmaceutical management. Similarly, adding the DDS-2 to the admission assessment, stating to only complete for PWDs, can initiate a BPA to add a diabetes distress care plan and the need for further assessment using the DDS-17 prior to discharge. A templated note could be made to document the DDS-17 scores. The care plan template could detail steps to address the diabetes distress and the education documentation tab could link the corresponding educational materials based on the subscales. The BPA could also suggest entering a consult

to the diabetes educator if the patient scores a high level of diabetes distress or upon patient request.

Automating the process of identifying and screening PWDs was another suggestion provided by the Diabetes Champions. A report created within the EMR could populate all patients with diabetes mellitus documented in their medical history and their last documented orientation assessment. This would allow the Diabetes Champions to view the report and quickly identify patients for screening without needing to perform a chart review or ask the care nurse if the patient meets criteria. It also could have alerted me to the change in mental status in the one incidence when the patient was oriented during the DDS-2 screening but was altered when the DDS-17 was attempted. The screening process could be automated by creating an online survey. The patients could respond to the DDS-2 screening and the remainder of the DDS-17 could populate if they score positive on the DDS-2. This process would be faster and auto-calculate the overall and subscale scores; then, nurses would only need to provide the education or add it to the discharge summary. These solutions can increase the ease of the screening process and incorporating it into standard practice but, as evidenced by Yared et al. (2020) and McGrath et al. (2021), we continue to need to find innovative ways to overcome barriers in both outpatient and inpatient settings.

Due to the length of the guided discussions ranging from 25 minutes to over an hour, this facet of the intervention would not be feasible in an inpatient setting. However, it could be shortened by combining questions 1 and 2 (see Table 1) to begin the conversation, since many of the PWDs discussed question 2 during their response to question 1. Question 3 and 4 also elicited similar responses. Question 3 may be better served as a prompt to discuss ways to focus on feelings and form realistic expectations rather than as a question to ask the

PWD (Fisher, Polonsky, & Hessler, 2019). Then to end the interaction with goal setting, question 4 should be asked and follow-up plans considered. These modifications would reduce the number of questions asked from five to two, reduce the amount of time spent by eliminating some repetition, and still follow the five-step plan recommended by Fisher, Polonsky, & Hessler (2019).

The next steps in this quality improvement process should be to develop automated screening tools, update the Duke Diabetes Care Handbook to include the new content areas used in this project, and trial documenting the diabetes distress screenings in a templated note. This implementation would decrease the time spent during diabetes distress screenings, standardize the educational materials, and increase provider awareness of diabetes distress in their patients. More data to support the significance and feasibility of these practices would be required before hospital leadership and practice committees would approve its incorporation into standard nursing assessments and the creation of BPAs.

Limitations

The inpatient hospital setting has high potential for missed screening opportunities due to its labile nature. Patients are constantly going for procedures and tests, not feeling well enough to participate in a screening, having unexpected changes in their condition, and often being discharged on short notice. These unpredictable situations exacerbated the missed opportunities to participate in the intervention since the intervention was only being conducted by the project lead when available. The limitations of the screening process were the voluntary nature of the project, the attrition of Diabetes Champion volunteers, and the workload of the participating Diabetes Champions which resulted in not being able to reach every PWD meeting inclusion criteria on these units. The main limitation in evaluating the

effectiveness of the intervention was the inability to contact the PWDs for the post-intervention follow-up after discharge. Limitations to the educational materials were lack of resources for non-English speaking, illiterate, or visually impaired patients. This did limit participation of patients whose first language was not English as the educational materials in their entirety were only available in English, but they were not excluded outright without assessing the patient's ability to utilize the educational materials.

Conclusions

The results of this project provide insight into the characteristics of those with diabetes distress in the inpatient population on general medicine and cardiology units in an academic health center, the perceived impact diabetes distress has on their lives, and the appropriate screening and educational materials to identify and address diabetes distress. This is one of the first projects focused on diabetes distress using inpatients as participants. Additional work is needed on this patient population due to the high levels of distress found and occurrence of triggering stimuli for distress surrounding hospitalization. To improve the feasibility and sustainability of screening, studies should explore ways to incorporate it into an existing standard practice and automating the process using reports or screening prompts within electronic medical records. Staff education emphasizing the rationale and benefits of the screenings is recommended to increase engagement. The educational intervention utilized may be adapted for use in inpatient or outpatient settings. Standard education for patients with diabetes can also be updated to include content on diabetes distress, positive coping strategies, and resources for peer support groups based on the higher rates of distress in these areas and demand for these resources. As this project constituted the first step in the process, quality improvement efforts continue to be necessary to develop consistent practice of

screening for and addressing diabetes distress in inpatients and address the identified barriers

to implementation.

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Appendix A
DDS

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".

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	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

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
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

DDS1.1 SCORING SHEET

<u>INSTRUCTIONS FOR SCORING</u>:

The DDS17 yields a total diabetes distress score plus 4 subscale scores, each addressing a different kind of distress.[1] To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale.

Current research[2] suggests that a mean item score 2.0 – 2.9 should be considered 'moderate distress,' and a mean item score $\geq$ 3.0 should be considered 'high distress.'   Current research also indicates that associations between DDS scores and behavioral management and biological variables (e.g., A1C) occur with DDS scores of $\geq$ 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 $\geq$ 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 $\geq$ 2) yes_____ no___

1. Polonsky, W.H., Fisher, L., Esarles, J., Dudl, R.J., Lees, J., Mullan, J.T., Jackson, R. (2005). Assessing psychosocial distress in diabetes: Development of the Diabetes Distress Scale. <u>Diabetes Care</u>, 28, 626-631.

2. Fisher, L., Hessler, D.M., Polonsky, W.H., Mullan, J. (2012). When is diabetes distress clinically meaningful? Establishing cut-points for the Diabetes Distress Scale. <u>Diabetes Care</u>, 35, 259-264.

Note. This copyrighted scale (Appendix A, DDS) is available free of charge to non-profit institutions for use in clinical care and research.

https://behavioraldiabetes.org/scales-and-measures/#1640736452460-7419c58b-9d36

Educational Resources by Diabetes Distress Subscale

Elevated Diabetes Distress Subscale	Educational Materials Provided
Emotional Burden	- Duke Diabetes Care Handbook "Diabetes Distress: Dealing with the Weight of Diabetes" by ADCES "Diabetes Distress" by ADA "ADCES7 Self-Care Behaviors: Healthy Coping" "12 Reframes to Deal with Diabetes Burnout or Distress" by DiabetesEd.net - Duke Healthwise Videos: "Diabetes: How Others Stay Motivated" "A Good Support System is Important"
Physician-related Distress	- Duke Diabetes Care Handbook "Diabetes Distress: Dealing with the Weight of Diabetes" by ADCES "Diabetes Distress" by ADA "Diabetes Self-Management Support Resources" by DukeHealth - Duke Healthwise Videos: "5 Tips to Keep Your Healthy Lifestyle Change Going" "Diabetes: 3 Steps to Problem-Solving"
Regimen-related Distress	- Duke Diabetes Care Handbook "Diabetes Distress: Dealing with the Weight of Diabetes" by ADCES "Diabetes Distress" by ADA "Diabetes Self-Management Support Resources" by DukeHealth - Duke Healthwise Videos: "5 Tips to Keep Your Healthy Lifestyle Change Going" "Diabetes: 3 Steps to Problem-Solving" "Diabetes: How Others Stay Motivated" "How Others Manage Diabetes"

Elevated Diabetes Distress Subscale	Educational Materials Provided
Interpersonal Distress	- Duke Diabetes Care Handbook "Diabetes Distress: Dealing with the Weight of Diabetes" by ADCES "Diabetes Distress" by ADA "Peer Support for Diabetes" by ADA "Learn, Connect, Engage" by ADCES "Diabetes Self-Management Support Resources" by DukeHealth - Duke Healthwise Videos: "A Good Support System is Important"

Note. ADCES = Association of Diabetes Care and Education Specialists, ADA = American Diabetes Association

Appendix C

Guided Discussion Response Frequency, Statements, and Thematic Determination by DDS-17 Subscale

Subscale	#	Statements/Quotes
Emotional Burden		
Defeat	6	• I'm doing everything right but it's still not working • "Stopped me from functioning" • "Slows me down, not able to keep up with it" • "When something gets hard for me to do, I just shut down. I have a different mood everyday where I can push past it and do my care tasks and others I am just done and don't want to push myself" • "Do I even want to or how do I deal with it?"
Exhaustion	5	• "Exhausting" • "It's a whole other life that you have to figure out to manage the disease" • "I'm tired of doing it" • "It's depressing, it's all day, it never stops, and never a day off"
Fear/Worry	6	• "This is it, it's gonna take me out" • Diabetes is the first thing I think of before I do anything • Always having to prepare for low blood sugars • "Scared"
Guilt	2	• "Guilt" • "Put myself down" • "Just throw up my hands and feel bad about it afterwards"
Physician-related Distress		
Poor Communication	2	• They don't help me understand what to do

Subscale	#	Statements/Quotes
Regimen-related Distress		
Difficulty with medications/Blood glucose checks	8	• Trouble with affording medications • Scared of needles • Fingers are numb from lancets so avoiding checking blood sugar • Stress about taking the right insulin at the right time
Difficulty with diet	7	• "Tough relationship with food" • "It takes a lot of effort and having to use my focus in it" • "Sometimes I have a 'I don't give a S---' attitude and eat what I want" • Carb counting was overwhelming • Sometimes skipping meals just to avoid high blood sugars
Difficulty managing diabetes and other chronic illnesses	3	• It's hard to keep up with medications on dialysis days
Interpersonal Distress		
Caregiving/Burdening others	3	• "Not their burden to take care of me" • "Worried about being a burden to someone else" • "It's always me last"
Unsupportive family	6	• "They don't understand so I don't tell them everything" • "They don't have enough information to support me but don't take any information from me" • Make me feel guilty for what I eat while making poor food choices in front of me • "No one seems to have time to help you. No one else wants to take on that other part of your life"

Note. # = number of times the concept was mentioned by different participants

Vita

Kirsten Hering was born in Raleigh, North Carolina, to Ricky and Jackie Hering. She graduated with a Bachelor of Science in Nursing from East Carolina University in December 2016. She began working on a General Medicine Stepdown unit at Duke University Hospital in February 2017. Over the years, she obtained board certification in Medical Surgical Nursing from the American Nurses Credentialing Center and currently serves as the Assistant Nurse Manager for that unit. In the fall of 2022, she completed the Master of Nursing in Education program at Appalachian State University, for which this thesis was completed. She plans to pursue certification as a Diabetes Care and Education Specialist.

Kirsten is an active member of both the North Carolina Nursing Association and the American Nursing Association. She resides in Durham, NC, with her husband and five cats.