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DIABETES DISTRESS IN U.S. ADULTS DURING THE COVID-19 PANDEMIC: A
SYSTEMATIC REVIEW

A Dissertation

Presented to the Faculty of
Antioch University New England

In partial fulfillment for the degree of
DOCTOR OF PSYCHOLOGY

by

Joanna Leah Sullivan

ORCID Scholar No. 0009-0001-9061-1686

November 2023

DIABETES DISTRESS IN U.S. ADULTS DURING THE COVID-19 PANDEMIC: A
SYSTEMATIC REVIEW

This dissertation, by Joanna Leah Sullivan, has
been approved by the committee members signed below
who recommend that it be accepted by the faculty of
Antioch University New England
in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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ABSTRACT

DIABETES DISTRESS IN U.S. ADULTS DURING THE COVID-19 PANDEMIC: A SYSTEMATIC REVIEW

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Diabetes mellitus (DM) is a common metabolic disease that continues to grow in prevalence, affecting around 11% of the U.S. population in 2019. Although DM has a clear medical cause, a growing body of research points to social determinants of health (SDOH) and psychosocial factors as important mediators of prevalence and severity of DM. Diabetes distress, a mental health phenomenon arising out of the challenges of living with a stigmatized and demanding chronic disease, is one such factor. Given the heightened effect of the COVID-19 pandemic on psychosocial stressors and vulnerability to mental health disorders, it is important to understand the impact of the pandemic on prevalence and severity of diabetes distress. This systematic review examines the experience of diabetes distress in U.S. adults during the COVID-19 pandemic with a narrowed focus on both systemic and psychosocial factors, as well as consideration of obstacles for future research and treatment directions with this population. A search of four databases resulted in 875 titles and abstracts that were screened against the inclusion and exclusion criteria that are standard in this type of analysis. Ultimately, four studies met criteria and were used in this review. It is possible that the overall, fair quality of the evidence along with a lack of consistent outcome reporting is reflected in the results, which indicated no obvious trends emerged. There is an urgent need for additional research in this area, particularly focused on improving assessment of diabetes distress and towards addressing

psychosocial factors in treatment of DM. This dissertation is available in open access at AURA (<https://aura.antioch.edu>) and OhioLINK ETD Center (<https://etd.ohiolink.edu>).

Keywords: diabetes distress, COVID-19, U.S. adults, systematic review

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CHAPTER I: INTRODUCTION

Diabetes mellitus (DM) is a common and potentially devastating chronic metabolic disease, which is estimated to affect 6.1% of people worldwide (Ong et al., 2023). According to the Centers for Disease Control and Prevention (CDC; 2022a), the prevalence rate for all types of DM in the U.S. population was around 11% in 2019. These numbers are only projected to grow, due in part to the rise in body mass index (BMI) worldwide that is driving an increased prevalence of type 2 diabetes mellitus (T2DM; Ong et al., 2023).

Although DM is a medical condition, research has revealed a mental health phenomenon unique to people with DM. *Diabetes distress* has been defined as “the negative emotional impact of living with diabetes” (Dennick et al., 2017, p. 898). Diabetes distress is associated with poorer DM outcomes, including both higher blood glucose levels over time and reduced diabetic self-care behaviors.

Public health research has also uncovered a complex interplay between the lifestyle factors that impact DM prevalence and outcomes with social determinants of health (SDOH; Hill-Briggs et al., 2020). SDOH are defined by the World Health Organization (WHO; n.d.) as the “non-medical factors that influence health outcomes” (para. 1). Examples of SDOH include lack of financial resources; limited education; unemployment and job insecurity; lack of access to quality healthcare; and social exclusion and discrimination. Research indicates that racial and ethnic minorities, as well as low-income individuals, are at greatest risk for developing T2DM and for poorer DM outcomes (Hill-Briggs et al., 2020). These disparities are driven in part by systemic inequalities, including a lack of access to quality healthcare; lack of financial resources to pay for treatment; and environmental factors that contribute to poorer health overall, including pollution, limited access to quality food, and lack of walkable neighborhoods.

Existing health disparities were amplified even further during the recent COVID-19 pandemic. People of color, under-resourced individuals, the unhoused, older and younger individuals, and women were among those experiencing significant disparities, including increased vulnerability to severe infection and death, during the COVID-19 pandemic (WHO, 2021). DM was a significant risk factor, and people with DM had three times the risk for severe COVID-19 infection (Gregory et al., 2021). Generally speaking, individuals living with DM were more likely to experience more total risk factors, which further increased their overall susceptibility to COVID-19 (CDC, 2023). Those with chronic diseases such as hypertension, autoimmune diseases, and kidney disease, as well as mental health conditions such as depression, anxiety, and severe mental illness were generally most vulnerable to COVID-19 infection and death (Kompaniyets et al., 2021).

On May 5, 2023, more than three years after the start of the COVID-19 pandemic, the WHO Director-General declared the end of the COVID-19 global health emergency (Ghebreyesus, 2023). Even as the world has moved into a post-pandemic era, the disruptive effects of COVID-19 on health and mental health continue to be explored and quantified. Although the concept of diabetes distress has been studied since its introduction in the literature by Polonsky et al. (1995), less is known about the interplay between DM, diabetes distress, and the COVID-19 pandemic, particularly in the U.S. Understanding how the COVID-19 pandemic affected prevalence and severity of diabetes distress may provide valuable insight into the effects of severe psychosocial stress and SDOH for psychological treatment of people with diabetes moving forward.

CHAPTER II: LITERATURE REVIEW

Diabetes Mellitus

Description and Subtypes

DM is a metabolic disease, characterized by the body's inability to properly control blood glucose (Sapra & Bhandari, 2023). There are several subtypes of DM, including type 1 (T1DM), type 2 (T2DM), and gestational diabetes. T2DM is the most commonly diagnosed subtype, comprising 90% of all DM diagnoses, with most patients requiring lifelong treatment or management once diagnosed. Left untreated, any DM subtype can be fatal. Additionally, DM can result in secondary complications, such as heart disease, neuropathy (nerve damage), vision loss, chronic kidney disease, hearing loss, and circulatory issues that often lead to problems, especially in the feet, and stands as a major cause of disability worldwide (Balaji et al., 2019; Ong et al., 2023). When DM is poorly managed, the risk of developing these complications increases dramatically.

Unlike T2DM, T1DM most often develops in childhood or early adulthood, as a result of the patient's own immune system attacking the body's insulin-producing cells created in the pancreas (Sapra & Bhandari, 2023). In T2DM, the body stops responding to insulin as it should, due to a "complex interplay between genetics and lifestyle" (Sapra & Bhandari, 2023, Etiology section). T2DM can develop at any age, although risk increases over the lifespan, and those with higher BMI are at greater risk. Gestational diabetes is diagnosed during pregnancy and is resolved upon delivery of the fetus. It also increases the risk of pregnancy complications, and the risk of eventually developing T2DM. The etiology of gestational diabetes is unknown, but it is thought to have an immune system or hormonal component. (CDC, 2022b).

Key Statistics and Risk Factors

In 2021, 529 million or 6.1% of individuals worldwide were living with DM (Ong et al., 2023). This number is projected to grow to 1.31 billion individuals by 2050. The CDC (2022a) has estimated that 11.3% of the U.S. population was living with DM in 2019; however, not everyone has the same risk for DM, and SDOH are a significant mediator of prevalence. Obesity, known to be a major risk factor for DM, is positively associated with SDOH burden, with the most socially disadvantaged individuals showing a 50–70% increase in obesity prevalence (Javed et al., 2022). SDOH burden is also positively associated with greater overall risk of developing T2DM.

Racial disparities exist among Americans diagnosed with DM, with non-Latinx White Americans being diagnosed at a rate of 7.4% (CDC, 2022a). Indigenous Americans have the highest risk for DM diagnosis at 14.5%, followed by Black Americans, Latinx Americans, and Asian Americans at 12.1, 11.8, and 9.5%, respectively. Disparities in DM risk have also been found among those with 12 or fewer years of education and under-resourced individuals, with those whose incomes fall below the federal poverty level being at the greatest risk.

Canedo et al. (2018) found that a portion of the observed racial and ethnic disparities in T2DM were explained by systemic socioeconomic disparities, including lack of health insurance and limited education. People of color with post-secondary educations and financial resources to pay for medical care were less likely to develop T2DM and more likely to receive appropriate tests and screenings from their medical providers. Other salient factors that contribute to the racial and ethnic disparities in development of T2DM include environmental factors, including exposure to pollution, and lack of walkability; limited access to high quality food; food insecurity; and lack of access to affordable, high-quality healthcare (Hill-Briggs et al., 2020).

History

DM has been observed and described by various civilizations for thousands of years. The Ebers Papyrus (c. 1500 B.C.E.), an ancient Egyptian medical document, described a disease known to cause polyuria, or excess urination, which is thought by some to be the earliest surviving written description of DM (Loriaux, 2006). Greek physicians in the 2nd century and Indian, Chinese, and Japanese physicians in the 5th and 6th centuries also wrote accounts of a disease consistent with DM, including recognizing sweet-tasting urine as an important sign (MacFarlane, 1990). Although various treatments were prescribed for this DM-like ailment, DM was usually fatal as none addressed the inability of the body to regulate blood glucose levels.

Between the 17th and 20th centuries, the mysteries of DM became less obscure. Much like their earlier counterparts, European physicians made the same observation that the urine of patients with DM tasted sweet (MacFarlane, 1990). By the early 20th century, through the identification of the purpose of the pancreas and the isolation of the hormone (insulin) it produced, a Canadian physician and his colleagues demonstrated that a deficiency of insulin was the cause of DM (Sapra & Bhandari, 2023). This breakthrough in understanding DM drove innovations in treatment and resulted in increased life expectancy of individuals with the disease.

Treatment and Management

Successful treatment and management of DM is typically multi-pronged and may include diabetes education, lifestyle changes, and medication (Sapra & Bhandari, 2023). Bariatric surgery also has the potential to normalize blood glucose levels in T2DM patients with high BMI. Once diagnosed, patients typically require lifelong management. T2DM is, in some cases, reversible with lifestyle changes, but the condition is likely to return if those alterations are not maintained (Ong et al., 2023). Patient education is a crucial component of DM management and

longer-term improvements. Health behaviors, such as maintaining a low carbohydrate diet and engaging in regular exercise, are routinely tied to better health outcomes. Additionally, patients able to monitor glucose levels independently have better overall outcomes. Difficulties with treatment adherence can result in high blood glucose levels and may lead to devastating health consequences. In addition to patient self-monitoring of their own blood glucose levels at discrete points of time, average blood glucose levels can be monitored over time using the hemoglobin A1c (HbA1c) blood test (Sapra & Bhandari, 2023). The HbA1c test is reported as a percentage and can be used to calculate an average of blood glucose levels over the preceding three months. Much of the research about DM uses HbA1c as an outcome measure, and patients are considered to have well-managed DM if they consistently achieved HbA1c levels below 7%.

As DM rates have continued to rise, psychologists and other mental health professionals have become increasingly involved in DM management, as part of interdisciplinary teams, conducting group-based treatments, and working with patients one-on-one. Interventions used include psychoeducation, motivational interviewing, cognitive behavioral therapy (CBT), mindfulness-based interventions, and more. Psychologists are uniquely positioned to help patients achieve changes to lifestyle in support of DM management, including weight loss, increased physical activity, and dietary changes (Araújo-Soares et al., 2019; Hunter, 2016). Psychological treatment to address underlying mental health disorders is also key to ensuring patients are able to successfully manage diabetes (Pouwer et al., 2020). Additionally, psychologists bring extensive knowledge and training about human diversity, which positions them to address SDOH and other psychosocial factors on both an individual level with patients and on a systemic level through advocacy and policy change. Although psychosocial and

systemic issues are often overlooked, they have been shown to represent a vital part of successful DM management (Hill-Briggs et al., 2020).

Mental Health and Diabetes Mellitus

Depressive Disorders and Diabetes

The link between depressive disorders and DM is well-established. In a narrative review of the literature, Pouwer et al. (2020) described the relationship between depression and DM and concluded that depression is a significant risk factor for DM. Pouwer et al. also found that people with diabetes are two to three times more likely to experience depressive symptoms, which suggests that DM confers an increased risk of developing depressive disorders. Individuals with comorbid depression and DM experience impaired quality of life and a higher risk of diabetes complications, cognitive decline, and death. The factors that drive this bidirectional relationship are assumed to be a combination of behavioral and biological factors (Pouwer et al., 2020). Comorbid depression has a negative impact on patients' DM self-care behaviors and often results in poorer diet, reduced adherence to medication, reductions in frequency of blood glucose monitoring, and more missed medical appointments. Although research is limited in this area, there is evidence that higher HbA1c levels can induce depressive symptoms (Beran et al., 2022).

In regard to treatment for co-morbid depression in people with DM, antidepressant medication, collaborative care, cognitive behavioral therapy (CBT), and mindfulness-based cognitive therapy (MBCT) have all been shown to be effective in reducing depressive symptoms (Pouwer et al., 2020; van der Feltz-Cornelis et al., 2021). The evidence for the effect of psychological treatment on HbA1c is mixed and more research is needed in this area. What is clear from the research is that screening and treatment of mental health disorders in people with DM is essential.

Severe Mental Illness and Diabetes

DM is also known to be a significant comorbidity of serious mental illness (SMI), which includes severe bipolar disorder, severe major depressive disorder, schizophrenia, and schizoaffective disorder (American Psychiatric Association & Substance Abuse and Mental Health Service Administration, n.d.). Individuals with SMI are at greater risk for developing T2DM and experience poorer DM outcomes than their counterparts without SMI (Dorey et al., 2023). People with SMI are also more likely to experience DM complications. The increased risk of DM and DM complications is likely driven by a combination of factors, including difficulties interacting with the healthcare system, effects of antipsychotic medication on glucose control, and SMI symptoms interfering with DM self-care.

Research regarding psychological treatment of comorbid SMI and DM is extremely limited. Zabell et al. (2021) completed a scoping review of literature about treatment of comorbid SMI and DM that integrated patient choice of intervention. Zabell et al. concluded healthcare providers struggled to integrate treatment of SMI and DM, citing communication breakdown between various providers and struggles to integrate patient choice as key factors. More research is needed about how to best manage both SMI and DM in these vulnerable patients.

Diabetes Distress

Definition, History, and Etiology

Research regarding the relationship between mental health and DM has uncovered a mental health phenomenon specific to people with DM known as diabetes distress. Diabetes distress has been defined as the “negative emotional or affective experience resulting from the challenge of living with the demands of diabetes, regardless of the type of diabetes” (Skinner et

al., 2020, p. 393). Dennick et al. (2017) identified seven aspects of diabetes distress from the literature:

- distress or guilt related to treatment regimen
- worry or rumination about complications and comorbidities
- fears about hypoglycemia
- guilt or shame about weight or other lifestyle choices
- emotional distress or guilt about food and eating
- negative affect related to living with DM
- conflicts with friends and family about DM management strategies
- distress related to interacting with the healthcare system

Although depression and diabetes distress share commonalities, including low mood, guilt, and shame, research has demonstrated diabetes distress to be distinct from depression (Perrin et al., 2017). However, people with DM may be diagnosed with depression even when their symptoms could be better explained by diabetes distress due to the limitations of current screening methods.

The concept of diabetes distress was first introduced by Polonsky et al. (1995). Polonsky et al. (1995) developed the Problem Areas in Diabetes (PAID) scale, a 20-item self-report measure that sought to measure “diabetes-related psychosocial distress” (p. 754) and administered it to insulin-dependent women ($N = 451$) with T1DM and T2DM. The results of the study showed that higher levels of distress as measured by the PAID scale were associated with higher HbA1c levels and decreased adherence to self-care treatment regimens. The authors cautioned at that time that the results could not be generalized due to the homogeneity of the population studied and expressed the belief that the association between high levels of distress and higher A1c might be a “statistical artifact” (Polonsky et al., 1995, p. 759).

Building on the body of research conducted using the PAID scale, Polonsky et al. (2005) developed the Diabetes Distress Scale (DDS17). Importantly, the DDS17 represented an attempt to develop a measure for diabetes distress that integrated theoretical dimensions of diabetes distress from the literature at the time. Polonsky et al. (2005) utilized focus groups and factor analysis to elucidate four key dimensions of diabetes distress: emotional burden, physician-related distress, regimen-related distress, and diabetes-related interpersonal distress.

Despite early doubts, research has overwhelmingly validated the concept of diabetes distress and confirmed the relationship between diabetes distress and higher HbA1c levels (Perrin et al., 2017; Skinner et al., 2020). Higher levels of diabetes distress are also associated with reduced adherence of behavioral self-care management strategies. Furthermore, there is evidence that diabetes distress mediates the relationship between depression and elevated HbA1c (Van Bastelaar et al., 2010). Given the connection between high diabetes distress and negative outcomes, addressing diabetes distress is an important goal in the management of DM.

Although the body of literature about diabetes distress has continued to grow since 1995, there has been limited research regarding the etiology of diabetes distress (Skinner et al., 2020). Skinner et al. (2020) proposed two components that might lead to diabetes distress: the burden of having and managing DM and iatrogenic distress related to navigating the healthcare system as someone with a stigmatized chronic disease. It is notable that the research about treatment of diabetes distress has focused almost exclusively on changing the patient to fit better with the healthcare system, rather than addressing systemic issues in the healthcare system that may also be a cause of diabetes distress.

Prevalence and Key Statistics

Diabetes distress is widespread among people diagnosed with DM. Perrin et al. (2017) conducted a systematic review and meta-analysis of 55 studies that included participants with T2DM from various countries. Their analysis revealed a diabetes distress prevalence rate of 36% among people with T2DM, using established cutoffs for diabetes distress measures. Limitations included the heterogeneity of outcome measures and outcome reporting in the studies used for the meta-analysis and limited data available for analysis, given the fairly recent emergence of diabetes distress as a clinical phenomenon.

A selection of diabetes distress research from the U.S. on patients with T1DM revealed prevalence rates ranging from 30% in an urban academic medical practice (Masharani et al., 2022), 36% of patients recruited from a large academic medical center (McCarthy et al., 2019), and 42% of patients recruited from four community diabetes clinics (Fisher et al., 2016). More research is needed regarding prevalence rates of diabetes distress in patients with T1DM.

Assessment and Treatment

In order to effectively treat diabetes distress, it must be accurately assessed in patients with DM. Dennick et al. (2017) reviewed existing measures for quantifying diabetes distress, including the PAID scale, Diabetes Distress Scale (DDS), Type 1 Diabetes Distress Scale (T1-DDS), and others. They concluded that while the above measures all assess for aspects of diabetes distress, there is no single measure that meets “standards for assuring content validity” (Dennick et al., 2017, p. 909) or provides a comprehensive assessment for diabetes distress. Dennick et al. recommended that a new measure of diabetes distress be developed with special attention paid to ensuring sufficient content validity. The lack of content validity in commonly used measures is a significant limitation of diabetes distress research.

Schmidt et al. (2018) reviewed the effectiveness of psychological interventions in reducing diabetes distress. Their meta-analysis revealed that psychological interventions to reduce diabetes distress were effective, but positive effects on HbA1c were only seen when the interventions were specifically designed for diabetes. Ngan et al. (2021) completed a systematic review and meta-analysis of the effectiveness of mindfulness-based interventions on both diabetes distress and HbA1c. Although results of the meta-analysis were promising, with mindfulness-based interventions shown to be as effective in reducing both diabetes distress and HbA1c, the authors cautioned that the heterogeneity of the interventions and underpowered studies included in the meta-analysis might have led results to skew more toward significance.

COVID-19, Mental Health, and Diabetes

The effects of the COVID-19 pandemic on mental health continue to be studied and quantified. Numerous studies and systematic reviews have been published on this subject. An umbrella review of systematic reviews conducted using worldwide research from the early phase of the COVID-19 pandemic revealed “small but significant increases of depression, anxiety, and/or general mental health symptoms” (Witteveen et al., 2023, p. 1). Witteveen et al. (2023) found that depressive symptoms increased more than anxiety symptoms and that although the initial increase in symptoms appeared to coincide with social distancing measures (which had the indirect result of increasing social isolation), the increases in anxiety and depressive symptoms did not appear to regress to pre-pandemic levels following the lifting of social distancing measures. Female-identifying individuals and younger individuals were revealed to experience greater negative impacts to their mental health.

García-Lara et al. (2022) completed a systematic review ($n = 37$) and meta-analysis ($n = 11$) of studies assessing stress, distress, or anxiety in T1DM and T2DM patients during the

COVID-19 pandemic. They found significant prevalence increases of stress, distress, and anxiety in DM patients. García-Lara et al. also noted finding a higher prevalence of anxiety among DM patients than had been previously found in studies assessing the prevalence of anxiety in other groups during the pandemic, suggesting DM patients might be especially vulnerable to pandemic-driven symptom increases. García-Lara et al. identified multiple limitations of their systematic review and meta-analysis, including heterogeneity due to inclusion of T1DM and T2DM studies from various countries. They also noted that including data gathered during any point during the pandemic may have been another source of heterogeneity, as local infection rates and social restrictions changed during different phases of the pandemic and these time-based factors may have had an impact on the results. Finally, García-Lara et al. identified inclusion of studies using different data collection methods as another limitation of their work.

Purpose of the Study

As the pandemic progressed, both DM and mental health disorders were revealed as factors that increased risk of contracting severe COVID-19 and also increased risk of death from the infection (CDC, 2023). Having multiple co-morbidities amplified the risk. It seems likely that previously identified aspects of diabetes distress such as emotional burden, physician-related distress, regimen-related distress, and diabetes-related interpersonal distress were exacerbated by psychosocial stressors related to the COVID-19 pandemic. This systematic review is an attempt to elucidate the diabetes distress experience of people living with DM during the COVID-19 pandemic and to examine relevant psychosocial and systemic factors.

Research Questions

1. Did the COVID-19 pandemic effect the prevalence and severity of diabetes distress among U.S. adults diagnosed with DM?

2. Were there identifiable psychosocial factors that may have impacted rates of diabetes distress in U.S. adults during the pandemic?
3. Were there identifiable systemic factors that may have impacted rates of diabetes distress in U.S. adults during the pandemic?
4. What are the implications of diabetes distress experiences in U.S. adults during the pandemic, and the outlook for psychological treatment of diabetes distress moving forward?

CHAPTER III: METHODS

Selection Criteria

I referenced the 2020 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines during the systematic review process (Page et al., 2021). I designed a review protocol utilizing the following inclusion and exclusion criteria: Studies eligible for inclusion in the review included quantitative or mixed-methods, observational, cross-sectional or longitudinal studies conducted in the U.S. with data gathered during the COVID-19 pandemic. The review protocol was designed to limit sources of heterogeneity. I chose to include only studies conducted in the U.S. and only studies with a validated diabetes distress measure for this reason. Treatment studies were also excluded from this review, due to the likelihood that they would introduce selection bias, as patients willing to participate in a treatment study for diabetes distress, or another diabetes-related concern, might endorse higher levels of diabetes distress than the average person with DM.

Study participant criteria included adults diagnosed with T1DM or T2DM who were administered a validated, diabetes-distress measure as part of the study. Studies which included comparison groups of individuals without diabetes, or types of DM other than T1 or T2, were eligible for inclusion. Only studies available in the English language were considered for inclusion. Case studies or reports, studies with data not collected during the pandemic, systematic reviews or meta-analyses, letters to editors, book chapters, and conference reports were excluded.

Search Strategy

I used four databases to gather studies: PubMed, PsycINFO, MEDLINE, and EBSCOhost Academic Search Complete. I searched all databases using the Boolean terms to try to be as

comprehensive as possible. The search terms used included “diabetes distress OR diabetes related distress OR diabetes-specific emotional distress” AND “COVID-19 OR coronavirus OR 2019-nCoV OR SARS-CoV-2 or CoV-19.” These databases were last accessed for this review on September 16, 2023.

The database search resulted in 956 records of interest. After duplicates and ineligible studies were removed, 875 titles and abstracts were screened against the inclusion and exclusion criteria. Of the 875 studies screened, 841 were irrelevant to the topic. An additional 21 were excluded for not meeting the inclusion and exclusion criteria. Following the initial screening, I reviewed the full text of the remaining 13 articles. Of these 13 studies, four met inclusion criteria and were entered in this review. See Figure 1 in Appendix A for a PRISMA flow diagram of the process. A summary of the characteristics of the included studies is reported in Table 1 in Appendix B.

Data Extraction and Quality Assessment

With multiple diabetes distress measures in use and a lack of standard reporting for scores presented, there were challenges during both the data collection and synthesis processes for this systematic review. All four studies included in the review used different outcome reporting methods and analyses for the primary outcome, diabetes distress. Additionally, effect sizes, odds ratios, or other statistical methods used to quantify the significance of outcome measures presented were not included in two of the studies, which made further meaningful direct comparisons unattainable. As such, descriptive and narrative data were gathered from the included studies. Study objectives, design, period, population (including available demographic data), outcome measures administered, and a summary of the results with supporting statistical

data were extracted. See Tables 2 and 3 in Appendices C and D for summaries of the participant characteristics and study results.

Quality assessment to determine the strength of evidence reported in a systematic review is an important part of the PRISMA process (Page et al., 2021). Numerous quality assessment tools exist; however, quality assessment tools for observational studies are limited, and the majority of tools I found were designed for assessing the quality of treatment studies. Ultimately, I chose to use the National Heart, Lung, and Blood Institute (NHLBI; 2021) Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies to assess the included studies for bias. The NHLBI criteria have been used to assess observational cohort and cross-sectional studies for possible selection bias, information bias, measurement bias, and confounding of results. This is achieved by evaluating studies that meet review inclusion criteria and answering “yes,” “no,” “cannot determine,” “not applicable,” or “not reported” using the following 14 questions:

1. Was the research question or objective in this paper clearly stated?
2. Was the study population clearly specified and defined?
3. Was the participation rate of eligible persons at least 50%?
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?
5. Was a sample size justification, power description, or variance and effect estimates provided?
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?

7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?
10. Was the exposure(s) assessed more than once over time?
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?
12. Were the outcome assessors blinded to the exposure status of participants?
13. Was loss to follow-up after baseline 20% or less?
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)? (NHLBI, 2021, Quality Assessment for Observational section)

The results of the quality assessment are reported in Table 4 in Appendix E. The quality of the included studies varied significantly. Neither Myers et al. (2022) nor Patel et al. (2023) included sample size justifications, power estimates, or variance and effect calculations, limiting the generalizability of these studies and introducing possible selection bias. However, it is not uncommon for observational studies to omit power estimates or sample size justifications due to the inclusion of exploratory analyses as part of the study design (NHLBI; 2021). Patel et al. did not administer DDS17 or HbA1c assessments consistently to all patients and noted this as a limitation of the study results. This lack of consistency is a possible source of measurement bias.

Moreover, Abdoli et al. (2022) and Patel et al. did not account statistically for the possibility of confounding variables that might affect study results.

Amerson et al. (2022) presented data without significant quality issues and received a “good” rating. Abdoli et al. (2022) received a “fair” rating, in large part due to the lack of statistical adjustment for possible confounding variables. Myers et al. (2022) received a “fair” rating, as information was not provided to confirm that at least 50% of eligible individuals participated, and no effects sizes or odds ratios were reported. Patel et al. (2023) received a “poor” rating, due to a lack of effects sizes or odds ratios reported, a deficit in consistent measurement of study variables, greater than 20% participant loss to follow-up, and an absence of statistical adjustment for confounding variables. Overall, the quality of the included studies is fair, and this is an important consideration when interpreting the results of the review.

CHAPTER IV: RESULTS

Overview of Studies

After reviewing 875 possible studies, four studies met the established inclusion and exclusion criteria.

Abdoli et al., 2022

Abdoli et al. (2022) compared T1DM psychosocial comorbidities in a cross-sectional online survey of adults ($N = 1099$) sampled from four geographical regions of the U.S.: North, South, Midwest, and West. The study data were collected between April and June 2020.

Abdoli et al. (2022) measured diabetes distress using the Type 1-Diabetes Distress Scale (T1-DDS). Diabetes burnout was assessed using the Diabetes Burnout Scale (DBS) and depressive symptoms using the Patient Health Questionnaire-8 (PHQ-8). Note that the PHQ-8 is the Patient Health Questionnaire-9 (PHQ-9) with the question, “Over the last 2 weeks, how often have you been bothered by... thoughts that you would be better off dead or of hurting yourself in some way?” (Kroenke & Spitzer, 2002, p. 514) omitted. The PHQ-8 was developed as an alternative to the PHQ-9 when assessing depression as a secondary outcome of medical conditions or when study design limits the potential for follow-up of endorsed suicidal ideation and has similar psychometric properties to the PHQ-9 (Kroenke & Spitzer, 2002).

In addition to the validated measures described above, participants answered a series of yes/no questions designed to assess ways the COVID-19 pandemic had impacted their ability to manage their diabetes effectively. Specifically, participants were asked about pandemic related difficulties when accessing diabetes care, supplies, and medication; difficulty accessing healthy food and places to exercise; and financial difficulties. Abdoli et al. (2022) also assessed experiences with COVID-19 itself, including whether participants were complying with

preventative measures and had been tested for, or been diagnosed with or hospitalized for, COVID-19. Participants were also asked to self-report HbA1c scores. The mean HbA1c score of the sample was 6.96%, reflecting well-controlled DM on average.

Abdoli et al. (2022) found a positive association between endorsement of COVID-19 related difficulties and diabetes distress across all four regions of the U.S. They also found that higher levels of diabetes distress were positively correlated with higher HbA1c levels throughout the sample. Additionally, endorsement of COVID-19 related challenges was associated with higher odds of moderately severe to severe depressive symptoms across all four geographic regions of the U.S. Abdoli et al. concluded that the prevalence of diabetes distress, diabetes burnout, and diabetes depressive symptoms was comparable to other studies before the pandemic. They also noted that the questions asked about COVID-19 related difficulties had significant overlap with SDOH known to contribute to diabetes distress. Abdoli et al. concluded that their results highlighted the importance of regularly screening for mental and physical health in individuals with diabetes and addressing mental and physical health in treatment, as well as accounting for contextual regional factors.

Strengths of the Abdoli et al. (2022) study included the geographic diversity of the sample, the analyses of outcomes by region, and data regarding the possible impact of COVID-19 on DM management. Limitations included that the sample was comprised of largely White, female, highly educated, and high-income participants, which likely resulted in selection bias. Additionally, as all variables were self-reported by participants, including their HbA1c, this study did not include any objective data regarding DM outcomes. Finally, confounding variables were not accounted for in the analysis, which is another possible source of bias that may have impacted the results.

Amerson et al., 2022

Amerson et al. (2022) compared diabetes distress and self-reported health between two different cross-sectional groups of Alabama Medicaid covered patients diagnosed with T2DM. One group was surveyed before the COVID-19 pandemic and the other during the COVID-19 pandemic ($N = 1822$; COVID-19 group $n = 384$). The data was collected between March 2017 and October 2019 for the pre-COVID-19 group and between October 2020 and May 2021 for the COVID-19 group.

Amerson et al. (2022) administered the DDS17 to measure diabetes distress. Self-reported health was assessed using the Self-Reported Health Survey. Depressive symptoms were measured using the PHQ-8. Perceived psychological stress during the past month was measured using the Perceived Stress Scale (PSS). Diabetes management self-efficacy was measured using the Perceived Diabetes Self-Management Scale (PDSMS). Participants in the group surveyed during the pandemic were also asked a series of questions designed to measure the impact of COVID-19 on their medical care. Specifically, participants were asked if any of their medical appointments were cancelled or rescheduled or whether they had any telehealth visits, if they had any difficulty sourcing DM supplies or medications, or if they had experienced decreased income due to job losses.

Amerson et al. (2022) reported that an analysis of the demographic characteristics of the two groups revealed that the group of participants surveyed during the pandemic had multiple key differences. Specifically, the group surveyed during COVID-19 had a higher proportion of Black and female participants. Additionally, the pandemic group was more likely to be employed and more likely to live in urban areas. Before controlling for differences between the groups, the COVID-19 group had slightly higher perceived diabetes management self-efficacy, moderately

lower perceived psychological stress, and modestly lower diabetes distress. After controlling for demographic differences, diabetes distress, and DM severity, Amerson et al. found that participants in the COVID-19 group were more likely to endorse fair to poor health. However, the researchers cautioned that the cross-sectional design of the study did not allow for causation to be inferred between the pandemic and poor perceived health. Participants with poor perceived health also endorsed higher levels of depression, lower perceived diabetes management self-efficacy, higher psychological stress, and higher levels of diabetes distress. Despite predictions to the contrary, Amerson et al. did not find an association between the surveyed healthcare disruptions related to COVID-19 and poor perceived health. Amerson et al. concluded that their findings supported a negative impact of the pandemic on physical and mental health in low-income individuals with DM.

Strengths of the Amerson et al. (2022) study included the population-based sample (i.e., adults covered by Alabama Medicaid) that may more accurately reflect the demographics of Americans living with T2DM. Limitations included the study's cross-sectional design, as well as the demographic differences between the two groups which make it difficult to meaningfully compare the groups to each other. Additionally, an objective measure of DM management (e.g., HbA1c) was not administered or collected and, thus, all the data gathered was self-reported by participants.

Myers et al., 2022

Using a cross-sectional online survey, Myers et al. (2022) compared the mental health of U.S. adults with and without DM during COVID-19 ($N = 2176$; T1DM and T2DM $n = 401$). Study data was gathered between May 29, 2020, and June 30, 2020. Diabetes distress was measured in the participants with T1DM and T2DM with the use of the DDS17. Myers et al.

administered the PHQ-8, Generalized Anxiety Disorder-7 (GAD-7), PSS, and Brief Resilience Scale (BRS) to assess participant mental health. Similar to other studies, sample participants were asked to self-report their most recent HbA1c and comorbid health conditions. The mean HbA1c score of the sample was 7.17%, suggesting fairly well-controlled DM on average. The effect of COVID-19 on participants was assessed using questions about being diagnosed with COVID-19, changes in income or employment as a result of the pandemic, and overall financial stability.

Myers et al. (2022) reported multiple trends with regard to mental health and DM. They noted that participants with T2DM were more likely than the rest of the sample to have multiple comorbid health conditions that increased their risk for severe COVID-19. After controlling for demographic variables, participants with T2DM were also more likely to endorse higher levels of depression and stress. The majority of participants with T1DM or T2DM endorsed moderate or severe diabetes distress, with T1DM participants endorsing slightly higher diabetes distress than T2DM participants. Myers et al. noted that this was higher than was observed in similar studies before the pandemic. Female participants scored higher on all mental health outcome measures. Black participants endorsed significantly higher rates of DM than other races but reported the lowest levels of mental health symptoms, which the authors hypothesized was a result of resilience to uncertainty and financial stressors. Younger participants (ages 18 to 34) had the highest levels of mental health symptoms compared to other age groups. Myers et al. noted that their findings served to add to the body of literature quantifying the emotional burden of the pandemic on individuals with and without DM.

Strengths of the Myers et al. (2022) study included the comparison group of participants without DM and the robust statistical analyses performed and reported. The geographic diversity

of participants was another strength, as the sample was recruited from across the U.S.

Limitations included the cross-sectional design of the study and the lack of objective outcome data. Another limitation is the size of the comparison group of individuals without DM, which was larger than the relatively small subset of participants with T1DM and T2DM. Additionally, the majority of the sample was comprised of White, female, highly educated, and high-income participants that do not reflect U.S. demographics and thus was likely to result in selection bias that may have impacted the results.

Patel et al., 2023

Patel et al. (2023) assessed diabetes distress and glycemic control over time in a group of uninsured patients with DM before and during the pandemic ($N = 328$). Patient data was gathered from the University of Alabama Providing Access to Healthcare (PATH) clinic, which serves uninsured patients with poorly controlled DM. Data gathered before April 1, 2020, comprised the pre-COVID period. The Stage 1 period included data gathered from April 1, 2020, to September 30, 2020. Data collected from October 1, 2020, to March 31, 2021, made up the Stage 2 period. Diabetes distress was measured using the DDS17, which was administered to participants if they had a positive result on the Diabetes Distress Screening Scale 2 (DDS2). Glycemic control was assessed using HbA1c levels measured by the PATH clinic as a part of routine care. Mean HbA1c scores of participants were 11.31% pre-COVID, 12.13% at Stage 1, and 10.79% at Stage 2, which reflected poorly controlled DM on average during all stages.

Patel et al. (2023) found that the prevalence of diabetes distress was higher in the sample than the general population before the start of the pandemic. Prevalence rates of diabetes distress in the sample fell to levels comparable to the general population during Stages 1 and 2. However, severity of diabetes distress increased during Stage 1 and did not return to pre-COVID levels in

Stage 2. HbA1c levels of participants increased between pre-COVID and Stage 1 and then decreased to below pre-COVID levels in Stage 2. Patel et al. concluded that screening patients for diabetes distress allowed the clinic to react quickly to logistical challenges caused by the pandemic, resulting in reduced diabetes distress and better blood glucose control.

Strengths of the Patel et al. (2023) study include the longitudinal design and objective measurement of glycemic control (i.e., HbA1c). Limitations include the specificity of the population sampled (uninsured patients of the University of Alabama PATH clinic) and inconsistent collection of both HbA1c and DDS17 data. Patel et al. also lost a significant number of participants to follow-up. Only 55 of the 328 patients completed all three screenings. Inconsistent data collection is a possible source of measurement bias and may have impacted the results.

Diabetes Distress During the Pandemic

Prevalence and Severity

The limited data points, as well as conflicting results from the included studies, make it difficult to draw overarching conclusions about the effects of the pandemic on the prevalence and severity of diabetes distress during the COVID-19 pandemic. Abdoli et al. (2022) found that diabetes distress prevalence in their sample during COVID-19 was similar to prevalence before the pandemic. Amerson et al. (2022) reported modestly lower severity of diabetes distress in the COVID-19 group compared to the pre-pandemic group. Myers et al. (2022) reported significantly higher prevalence and severity of diabetes distress in their sample, as compared to other studies before the pandemic. Finally, Patel et al. (2023) observed higher prevalence and severity of diabetes distress in their sample compared to the general population before COVID-19. However, during the pandemic, the prevalence of diabetes distress fell to levels

comparable to the generable population while the severity increased at the start of the pandemic and had not returned to pre-COVID levels by the end of the study period.

Although the data did not speak to a universal experience of diabetes distress during the pandemic, the data uncovered that the experience of living with DM varied tremendously as a result of SDOH and demographic characteristics (Canedo et al., 2018; Hill-Briggs et al., 2020). Furthermore, the pandemic experience for those researched varied vastly based on demographic characteristics and SDOH (Abrams & Szeffler, 2020; WHO, 2021). Thus, diabetes distress does not occur in a vacuum. To effectively counter diabetes distress, particularly for the most vulnerable populations, it is essential for psychosocial and systemic factors to be addressed.

Psychosocial and Systemic Factors

Increased depression, anxiety, and stress in individuals with DM were recurrent themes across the study results (Abdoli et al., 2022; Amerson et al., 2022; Myers et al. 2022). The severity of mental health symptoms increased in the general population during the first few months of the pandemic (Salanti et al., 2022). However, a substantial body of evidence has revealed that this increase in severity was largely temporary and decreased over time (Sun et al., 2023). Given the lack of longitudinal data, it is difficult to know if a similar effect occurred with diabetes distress levels. Notably, two out of four studies reported on data gathered during the first three months of the pandemic, a fact which may have impacted the results. However, untangling a causal relationship between the pandemic, mental health symptoms, diabetes distress, and DM outcomes is beyond the scope of this review.

With regard to systemic factors, difficulties accessing healthcare and diabetes management supplies, as well as financial difficulties, were identified as impacting mental health and diabetes distress during the pandemic (Abdoli et al., 2022; Amerson et al., 2022; Myers et

al., 2022). What is less clear from the study results is whether these effects were unique to the pandemic or reflective of what is already known about the impact of systemic factors on physical and mental health.

CHAPTER V: DISCUSSION

The aim of this systematic review was to explore and summarize the literature about the effects of the COVID-19 pandemic on the prevalence and severity of diabetes distress for individuals in the U.S. diagnosed with T1DM or T2DM, as well as to highlight any relevant psychosocial and systemic factors. To that end, I searched four databases for possible studies and screened them against the inclusion and exclusion criteria outlined in Chapter III.

My search revealed very few studies published in the U.S. with data collected during the pandemic that examined diabetes distress using validated measures. The available studies that met my inclusion and exclusion criteria provided informative data about associations between diabetes distress, psychosocial and systemic factors, and the COVID-19 pandemic. However, due to design and quality considerations, causality cannot be inferred. Three of the studies were cross-sectional (Abdoli et al., 2022; Amerson et al., 2022; Myers et al., 2022); meanwhile, the one longitudinal study I reviewed had many missing data points and did not control for confounding factors (Patel et al., 2023).

Notably, the included studies differed significantly in their conclusions about the effects of the pandemic on diabetes distress, with some studies showing similar or slightly lower severity and prevalence compared to pre-pandemic studies (Abdoli et al., 2022; Amerson et al., 2022). Myers et al. (2022) reported significantly higher levels of diabetes distress severity and prevalence compared to pre-COVID studies. Finally, Patel et al. (2023) reported a decrease in prevalence of diabetes distress but an increase in severity over the first year of the pandemic.

Possible explanations for this lack of consensus include heterogeneous samples, limited data points, differing points during the pandemic at which data were collected, and non-standardized reporting of diabetes distress outcome measures. Two of the studies were

online surveys that recruited from across the U.S. (Abdoli et al., 2022; Myers et al., 2022). However, despite the geographical diversity of the samples, both studies overwhelmingly surveyed White, highly educated, high-income women. Given what is known about the demographics of DM and experiences of people of color and other diverse individuals vis-à-vis the healthcare system (and DM care in particular), these samples were unlikely to capture the experiences of a significant portion of people living with DM (Canedo et al., 2018; CDC, 2022a). The two remaining studies sampled distinct, vulnerable populations: Alabama Medicaid recipients and University of Alabama PATH clinic patients (Amerson et al., 2022; Patel et al., 2023). It is unsurprising that studies of such vastly different populations would achieve different results. Additionally, the limited data points offered by three cross-sectional studies and one longitudinal study proved to be insufficient for revealing any patterns that may have been present.

For the purposes of this review, studies including participants with T1DM and T2DM were eligible. While individuals with T1DM and T2DM share many commonalities and are often studied together, research has shown distinctions in their diabetes distress experiences, in that T1DM patients tend to experience greater prevalence and severity of diabetes distress (Akyirem et al., 2023; Fisher et al., 2016). Two of the studies reviewed included a mix of participants with T1DM and T2DM (Myers et al., 2022; Patel et al., 2023), one study included participants with T1DM only (Abdoli et al., 2022), and one study included participants with T2DM only (Amerson et al., 2022). This mix of participants with T1DM and T2DM may have confounded the results.

Differences in score reporting are another possible explanation for the differing results. Although three studies used the same diabetes distress outcome measure (DDS17; Amerson et

al., 2022; Myers et al., 2022; Patel et al., 2023), all three studies reported DDS17 scores differently. Amerson et al. (2022) reported median DDS17 scores, Myers et al. (2022) reported mean scores and a percentage breakdown of score ranges, and Patel et al. (2023) reported mean scores only. This lack of consistency in reporting of results makes direct comparisons difficult.

Another possible explanation for the disparity in results is the time period during the pandemic in which the data were collected. Research regarding the prevalence and severity of mental health disorders during the pandemic revealed an initial spike in mental health symptoms during the first few months of the pandemic, followed by a return to pre-COVID levels (Sun et al., 2023). Abdoli et al. (2022) and Myers et al. (2022) both collected data during the first four months of the pandemic, while Amerson et al. (2022) and Patel et al. (2023) collected data into the first year of the pandemic. It is possible there is a pattern of increased diabetes distress, followed by return to pre-pandemic levels that is confounding the results.

In regard to the effect of psychosocial and systemic factors on severity and prevalence of diabetes distress, three of the studies assessed psychosocial variables using validated self-report measures. Additionally, participants were asked questions designed to gather information about their experiences during the pandemic (Abdoli et al., 2022; Amerson et al., 2022; Myers et al., 2022). The results of the studies suggested psychosocial and systemic factors were associated with higher levels of diabetes distress. However, because of the lack of pre-pandemic data, it is impossible to know whether the associations between psychosocial and systemic factors and increased severity of diabetes distress were pre-existing or a result of the COVID-19 pandemic or a complex interaction of pre-existing and pandemic-specific factors.

Limitations

This systematic review has numerous limitations, several of which are related to the studies included in the review. The overall quality of the studies included was fair, and the studies had disparate results, making it difficult to make any useful generalizations. I chose to include studies of participants with T1DM, T2DM, or a mix of both, which may have obscured differences in prevalence and severity between the two types during COVID-19. Although I attempted to increase homogeneity by narrowing the search to studies conducted in the U.S., the study participants were heterogeneous. My attempt to increase homogeneity also resulted in very few data points, making it difficult to detect any trends that may have been present.

Another set of limitations is related to a lack of clarity around the definition and measurement of diabetes distress itself. As Skinner et al. (2020) outlined, existing diabetes distress measures may lack the depth and breadth necessary to quantify fully the experience of diabetes distress. Additionally, the lack of consensus regarding reporting of the results of diabetes distress measures makes it difficult to truly compare results between studies.

Other limitations include that I did not do a search for gray literature and that only one person screened studies for inclusion and possible biases. I also did not perform a meta-analysis to compare the results of the studies included (although a meta-analysis would have had significant limitations due to the manner in which scores were reported in the included studies).

Directions for Future Research

In order to improve the quality of diabetes distress research, it is vital to quantify the concept of diabetes distress and more completely describe how people with diabetes distress experience it. At present, researchers and providers rely on cutoff scores from self-report measures to assess for diabetes distress rather than applying evidence-based diagnostic criteria.

Little is known about the etiology of diabetes distress, and it is unclear what (if any) steps can be taken to prevent it. Systematic factors that may be contributing to the phenomenon are largely unexplored. This lack of clarity in definition and diagnosis makes high-quality research on the topic challenging. Additionally, research is needed regarding differences in symptom presentation, etiology, course, severity, and prevalence of diabetes distress between T1DM and T2DM. Focus groups exploring the experiences of people with T1DM and T2DM and subjecting existing research to factor analysis are two possible ways future researchers could develop a better understanding of diabetes distress. Ideally, a work group of medical providers and psychologists would then work together to develop evidence-based diagnostic criteria using the information gathered.

Once diabetes distress as a concept has been defined and diagnostic criteria outlined, development of an instrument to accurately measure prevalence and severity of diabetes distress is paramount. Given the overlap between depression and diabetes distress, it is essential that this instrument be able to differentiate between guilt, shame, and low mood related to diabetes distress versus global negative affect consistent with depressive disorders. Based on research regarding key differences in T1DM and T2DM diabetes distress symptomatology, separate measures for the two types may be indicated. Instruments should be designed to track changes in symptom presentation over time and standardized scoring is crucial.

In regard to future research about the severity and prevalence of diabetes distress, longitudinal studies using population-based samples would be ideal. As demonstrated by this systematic review, convenience samples are unlikely to capture the experience of many of the most marginalized people living with diabetes distress. Analyzing T1DM and T2DM data as subgroups rather than collapsing the data into one group only is preferred. Additionally, given the

relationship between diabetes distress and HbA1c, it is preferable that HbA1c scores be included as an outcome in diabetes distress research. Research exploring the etiology of diabetes distress and the systemic factors that may contribute to its development are both topics in need of further examination.

Implications for Psychological Practice

DM is a life-altering chronic disease with the potential for grievous consequences if inadequately untreated. Although directly treating the cause of DM (i.e., insulin deficiency) is outside the scope of psychological practice, a large body of research has revealed that mental health, in general, and diabetes distress, in particular, are closely tied to DM outcomes. Diabetes distress affects around 36% of people with T2DM and as many as 42% of people with T1DM and is correlated with higher HbA1c levels (Fisher et al., 2016; Perrin et al., 2017). Conversely, when diabetes distress is addressed using psychological treatment, HbA1c levels improve. A strictly biomedical approach to DM management is insufficient to address the complex interplay between SDOH, systemic health disparities, and psychosocial factors such as diabetes distress. However, despite the ample evidence that diabetes distress is ubiquitous, consequential, and responsive to psychological treatment, psychologists remain undertrained and underutilized in DM management (Hunter, 2016).

Given the evidence that psychological treatments are effective in treating diabetes distress and improving DM outcomes, screening for and treating diabetes distress should be implemented as the standard of care for individuals with DM. However, changes to practice guidelines are not enough. Implementation of changes in standards of care requires psychologists to be trained and equipped to work with people with DM. To that end, it is essential that the field of psychology as a whole and psychology training programs in particular recognize that chronic diseases, such as

DM and its complications, are social justice issues in need of redress. Not all individuals are equally vulnerable to developing DM or at risk for complications. People of color, under-resourced individuals, and older adults are at a higher risk for developing DM and suffering more significant DM complications than the general population (CDC, 2022a). The recent COVID-19 pandemic continues to be a stark reminder of the health disparities that exist in the U.S. and their devastating cost. Psychologists are uniquely poised to address both psychosocial and systemic issues that contribute to the burden of DM management, both within the context of treatment and as a part of advocacy efforts.

As this systematic review has shown, additional high-quality research about diabetes distress is needed. Three of the four studies reviewed had a significant risk of bias in at least one area, if not several. Research is also hampered by lack of standardized reporting and tracking of diabetes distress scores. Additionally, there is evidence that the current diabetes distress measures may not accurately capture the range of experience with diabetes distress (Skinner et al., 2020). Finally, although research has shown differences between the diabetes distress experiences of T1DM and T2DM, much is still unknown regarding these differences, as well as the most effective psychological interventions for each. Clinical and health service psychologists offer assessment development and administration skills urgently needed to facilitate the advancement of research about diabetes distress.

Conclusion

This systematic review examined diabetes distress among adults living with DM in the U.S. during the COVID-19 pandemic. Due to the paucity of appropriate studies identified on the topic, it is clear that more research is needed regarding the impact of COVID-19 on diabetes distress prevalence and severity. This review also highlighted overall issues with diabetes distress

research identified in other literature on the topic; specifically, lack of quality standardized assessments for diabetes distress, lack of standardization of scoring and score reporting, and T1DM and T2DM diabetes distress being studied together.

Utilization of the biomedical model to treat and manage DM has resulted in numerous breakthroughs. Patients have access to more interventions than ever before and yet prevalence rates of DM continue to rise. It is clear from the literature that the biomedical model alone does not address all the factors that contribute to DM risk, prevalence, and health outcomes. Despite the overwhelming evidence for the importance of addressing psychosocial concerns, the integration of salient factors, such as SDOH and diabetes distress, into DM treatment remains limited. The largely biomedical focus of DM treatment likely contributes to the limited body of research on diabetes distress.

The biomedical approach is insufficient to address rising rates of T2DM in particular. The biopsychosocial model should be adopted as best practice instead so as to better address both biomedical and psychosocial factors in individuals living with DM (Engel, 1977). If current trends continue, 1.31 billion individuals worldwide are expected to be diagnosed with DM by 2050 (Ong et al., 2023). From a psychological perspective, the outsize impact of the increase in DM prevalence on vulnerable and socially disadvantaged populations makes this trend a critical social justice issue.

One way to address psychosocial factors is to make assessment and treatment of diabetes distress an integral part of DM management, as higher levels of diabetes distress are correlated with higher HbA1c levels (Dennick et al., 2017; Fisher et al., 2016; Perrin et al., 2017). However, current research conceptualizes diabetes distress as a problem within the patient and has largely overlooked the role of systems in generating diabetes distress (Skinner et al., 2020).

Additionally, there is limited research about the interplay between SDOH, diabetes distress, and diabetes outcomes.

More research is needed on the etiology of diabetes distress, its role in DM management, and the best ways to intervene at both individual and systemic levels. Psychologists possess training and skills that would add value to future research about diabetes distress, particularly in regard to assessment development and administration, thus, positioning them to advocate for better assessment and treatment of diabetes distress in addressing systemic health disparities. With the dramatic increases in DM prevalence, more psychologists are needed in all levels of DM research to apply the biopsychosocial model to assessment and treatment frameworks.

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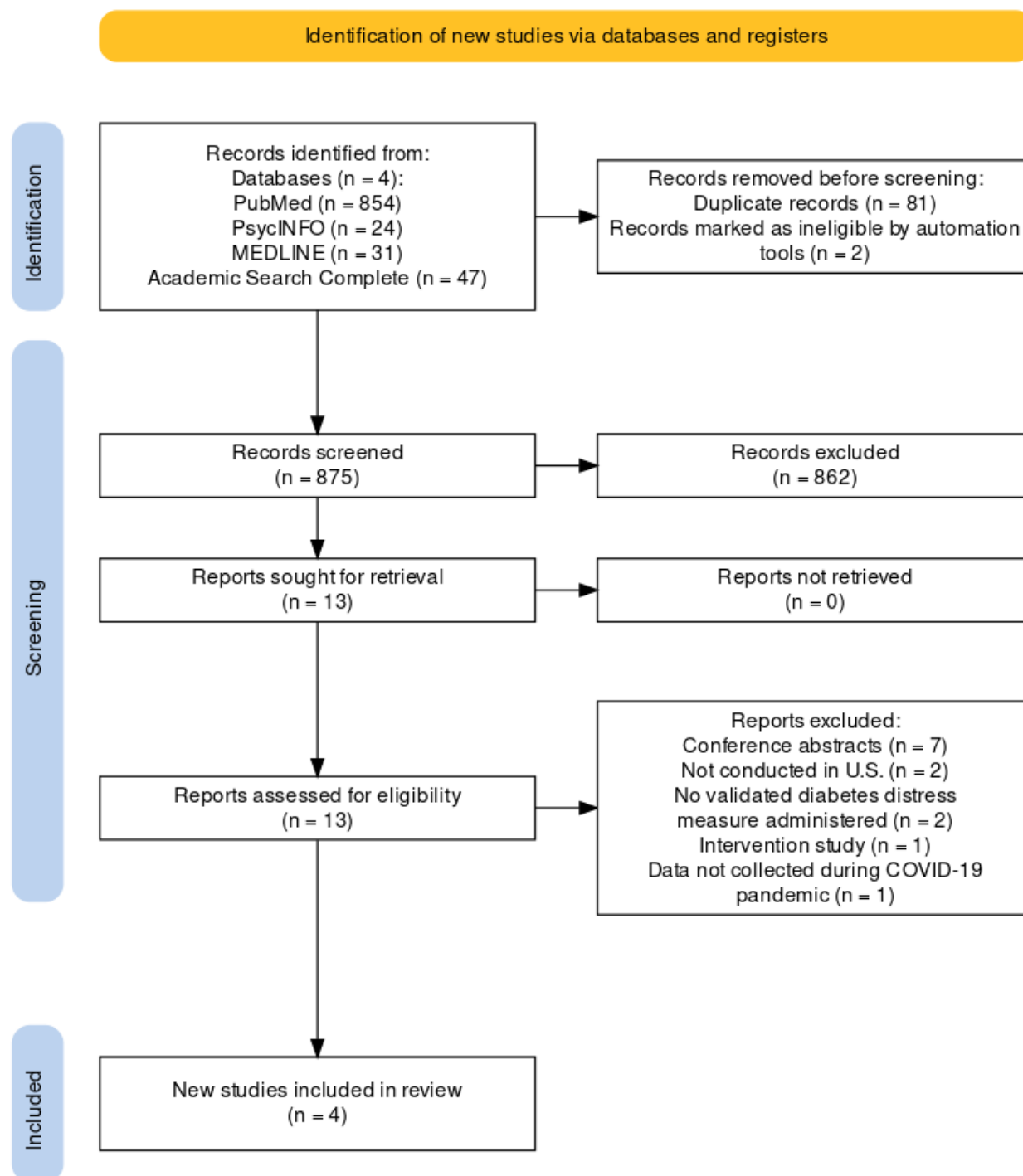
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APPENDIX A: PRISMA FLOW DIAGRAM

Figure 1

PRISMA Flow Diagram







(Haddaway et al., 2022)

APPENDIX B: CREATIVE COMMONS LICENSE FOR HADDAWAY ET AL., 2022

Figure 2

Creative Commons License for Haddaway et al., 2022



PRISMA2020: An R package and Shiny app for producing PRISMA 2020-compliant flow diagrams, with interactivity for optimised digital transparency and Open Synthesis

Author: Neal R. Haddaway, Matthew J. Page, Chris C. Pritchard, et al

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APPENDIX C: CHARACTERISTICS OF INCLUDED STUDIES

Table 1

Characteristics of Included Studies

Author, year	Study period(s)	DM type	Participants	Study design	Diabetes distress outcome
Abdoli et al., 2022	April 2020 – June 2020	T1DM	$N = 1099$ Recruited from Northeast, South, Midwest, and West regions of U.S.	Cross-sectional online survey	T1-DDS
Amerson et al., 2022	March 2017 – October 2019 and October 2020 – May 2021	T2DM	$N = 1822$ Alabama Medicaid covered patients	Cross-sectional survey	DDS17
Myers et al., 2022	May 29, 2020 – June 30, 2020	T1DM T2DM	$N = 2176$ T1DM $n = 100$, T2DM $n = 301$	Baseline data from a 12-month longitudinal observational study	DDS17
Patel et al., 2023	September 1, 2019 – March 31, 2021	Poorly controlled T1DM or T2DM	$N = 328$ Patients of University of Alabama Providing Access to Healthcare (PATH) clinic	Longitudinal observational study	DDS17

APPENDIX D: PARTICIPANT CHARACTERISTICS

Table 2

Participant Characteristics

Author, year	Mean age	Gender		Race and ethnicity		Education		Yearly income		Employment	
			%		%		%		%		%
Abdoli et al., 2022	45 ^a	Female	76 ^a	White	95 ^a	≤ High school	14 ^a	≤31,000	19 ^a	Full-time	51 ^a
		Male	24 ^a	Non- White	5 ^a	Associate degree	12 ^a	32,000-42,000	9 ^a	Part-time	10 ^a
						Bachelor degree	39 ^a	43,000-64,000	19 ^a	Unemployed	7 ^a
						Graduate degree	35 ^a	65,000-86,000	15 ^a	Self-employed	6 ^a
								87,000-107,000	13 ^a	Homemaker	5 ^a
								25% ≥108,000	25 ^a	Student	5 ^a
										Retired	15 ^a
										Other	3 ^a
										Working or studying	9
										Not working	19
Amerso n et al., 2022	^b	Female	82	Black	64	< High school	29	<10,000	67	Cannot work	72
		Male	18	White	33	High school	45				
				Other	3	> High school	25				
				Latinx	1						
Myers et al., 2022	56 ^a	Female	71 ^a	White	86 ^a	< High school	0 ^a	0-10,000	3 ^a	^b	
		Male	29 ^a	Black	8 ^a	High school or GED	5 ^a	10,001-20,000	7 ^a		
				Other	6 ^a	Trade school	5 ^a	20,001-40,000	21 ^a		
				Latinx	3 ^a	Some college	24 ^a	40,001-60,000	16 ^a		
						College degree	33 ^a	60,001-80,000	18 ^a		
						Master or postgraduate degree	33 ^a	80,001-100,000	11 ^a		
								>100,000	23 ^a		

Author, year	Mean age	Gender		Race and ethnicity		Education		Yearly income		Employment	
			%		%		%		%		%
Myers et al., 2022	56 ^a	Female	71 ^a	White	86 ^a	< High school	0 ^a	0-10,000	3 ^a	b	
		Male	29 ^a	Black	8 ^a	High school or	5 ^a	10,001-20,000	7 ^a		
				Other	6 ^a	GED		20,001-40,000	21 ^a		
				Latinx	3 ^a	Trade school	5 ^a	40,001-60,000	16 ^a		
						Some college	24 ^a	60,001-80,000	18 ^a		
						College degree	33 ^a	80,001-100,000	11 ^a		
						Master or	33 ^a	>100,000	23 ^a		
						postgraduate degree					
Patel et al., 2023	46	Male	56	Black	56 ^b					b	
		Female	44	White	34						
				Other	10						
				Unknown	<1						

^a Calculated from published data.

^b Data not reported

APPENDIX E: STUDY RESULTS

Table 3

Study Results

Author, year	Diabetes Distress Outcomes		Secondary Outcomes		Mean HbA1c
		%		%	
Abdoli et al., 2022	T1-DDS scores		Diabetes Burnout Scale (DBS)		6.97
	Mean = 2.1 ^a		Mean = 2.3 ^a		
	Moderate/high	46 ^a	Moderate/severe	23 ^a	
			Patient Health Questionnaire-8 (PHQ-8)		
Amerson et al., 2022			Mean = 6.9 ^a		
			Moderately severe/severe	26 ^a	
	DDS17 scores		Self-Reported Health		
	Mean = 1.2		Poor	53	
			PHQ-8		
			Median = 5		
			Perceived Diabetes Self-Management Scale (PDSMS)		
			Median = 30		
			Perceived Stress Scale (PSS)		
			Median = 5		

Author, year	Diabetes Distress Outcomes		Secondary Outcomes		Mean HbA1c
		%		%	
Myers et al., 2022	DDS17 scores		PHQ-8		7.17
	Mean = 2.5 ^a		Mean = 7.8 ^a		
	Moderate/high	62 ^a	Moderately severe/severe	33 ^a	
			Generalized Anxiety Disorder-7 (GAD-7)		
			Mean = 6 ^a		
			Positive for anxiety	25 ^a	
			PSS		
			Mean = 16.3 ^a		
Patel et al., 2023			Moderate/high	60 ^a	
			Brief Resilience Scale (BRS)		
			Mean = 20.7 ^a		
			Low resilience	1 ^a	
	DDS17 scores				Pre-COVID = 11.31
	Mean pre-COVID = 2.9				Stage 1 = 12.13
	Mean Stage 1 = 3.4				Stage 2 = 10.79
	Mean Stage 2 = 3.1				

^a Calculated from published data.

APPENDIX F: QUALITY ASSESSMENT TOOL FOR OBSERVATIONAL COHORT AND CROSS-SECTIONAL STUDIES

Table 4

Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Quality
Abdoli et al., 2022	Y	Y	Y	Y	Y	N	NA	NA	Y	NA	Y	NA	NA	N	Fair
Amerson et al., 2022	Y	Y	Y	Y	Y	N	NA	NA	Y	NA	Y	NA	NA	Y	Good
Myers et al., 2022	Y	Y	CD	Y	N	N	NA	NA	Y	NA	Y	NA	NA	Y	Fair
Patel et al., 2023	Y	Y	Y	Y	N	Y	Y	NA	Y	Y	N	NA	N	N	Poor

Note. Y = Yes, N = No, NA = not applicable, CD = cannot determine. Checklist publicly available online from the National Heart,

Lung, and Blood Institute (NHLBI; 2021). Retrieved from <https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools>.