MEASURING DIABETES DISTRESS IN EMERGING ADULTHOOD

a dissertation

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MEASURING DIABETES DISTRESS IN EMERGING ADULTHOOD KATHERINE WENTZELL JUDITH A. VESSEY, Dissertation Chair

Significance of Problem: Emerging adults (ages 18-30) with type 1 diabetes (T1D) are a specific group that experiences worse glycemic control, more frequent severe hypoglycemia and more frequent diabetic ketoacidosis (DKA) than any other age group. The multiple transitions and stressors associated with the developmental stage of emerging adulthood can magnify and exacerbate the diabetes specific emotional burden of living with T1D, resulting in increased diabetes distress (DD). However, there is no measure of DD specific to the developmental stage of emerging adulthood. **Purpose**: The purpose of this program of research is to explicate the need for a developmental stage-specific measure of DD, as well as to develop, refine and psychometrically validate a new measure of DD in emerging adults. Method: This multi-phase study employed methods grounded in both item response theory (Rasch analysis) and classical test theory to reduce, refine and validate a new measure of DD in emerging adulthood, entitled the Problem Areas in Diabetes-Emerging Adult version (PAID-EA). In phase 1, data were collected from emerging adults with T1D using a cross-sectional online survey strategy. Rasch methodology was used to reduce and refine the PAID-EA. In phase 2, an additional crosssectional online survey was conducted using the refined PAID-EA. Classical test theory-based approaches were employed to examine the psychometric properties of the refined measure. Finally, the relationships between scores on the PAID-EA and related constructs and clinical variables were explored. Conclusions: Collectively, this work advances the science by providing insight into how the challenges of emerging adulthood impact life with T1D during this developmental stage and providing a new measure to accurately and validly capture this experience for both clinical and research purposes.

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Table of Contents

	Page
Copyright	2
Abstract	3
Acknowledgements	4
Table of Contents	5
List of Tables	6
List of Figures	7
Chapters	
1. Introduction	8
2. <i>Manuscript 1</i> : How do the challenges of emerging adulthood inform our understanding of diabetes distress? An integrative review	23
3. <i>Manuscript 2:</i> Diabetes distress in emerging adults: Refining the Problem Areas in Diabetes—Emerging Adult version using Rasch analysis	56
4. <i>Manuscript 3:</i> Assessing diabetes distress in emerging adults: Development and validation of the Problem Areas in Diabetes— Emerging Adult version	80
5. Cumulative Discussion	105
Cumulative references	125
Appendix A. PAID-EA 25-item measure	150

List of Tables

	Page
Introduction: Table 1. Overall purpose and specific aims	19
Manuscript 1: Table 1. Quantitative studies exploring diabetes distress (DD) in emerging adults	45
Manuscript 1: Table 2. Qualitative studies exploring diabetes distress (DD) in emerging adults	52
Manuscript 2: Table 1. Participant characteristics	75
Manuscript 2: Table 2. Rasch item fit statistics for the 30-item PAID-EA	78
Manuscript 3: Table 1. Participant characteristics	101
Manuscript 3: Table 2. Item difficulties and component loadings for the PAID-EA	102
Cumulative Discussion: Table 1. Specific aims and findings	107
<i>Cumulative Discussion</i> : Table 2. Item difficulty from classical test theory analysis compared to Rasch analysis continuum	111

List of Figures

	Page
<i>Introduction:</i> Figure 1. Conceptual map of how developmental stage theory affects diabetes distress	17
Manuscript 2: Figure 1a. Variable map for 30-item PAID-EA	76
Manuscript 2: Figure 1b. Variable map for reduced 22-item PAID-EA	77
Manuscript 3: Figure 1. Scree plot	103
<i>Cumulative Discussion:</i> Figure 1. Conceptual map of how developmental stage theory affects diabetes distress	109

Chapter 1

Introduction

Approximately 1.4 million Americans live with type 1 diabetes (T1D) and both the prevalence and incidence of T1D have been increasing in recent years (Center for Disease Control and Prevention, 2020; Dabelea et al., 2014; Mayer-Davis et al., 2017). T1D results from the auto-immune destruction of insulin producing pancreatic beta cells, and is believed to be a consequence of a combination of genetics, environmental factors and multiple stochastic variables (Jeffrey, Kevan, & George, 2010). Intensive T1D management requires multiple complex daily tasks including blood glucose monitoring, carbohydrate counting and insulin administration (American Diabetes Association, 2020). The Diabetes Control and Complications Trial (DCCT) and the follow-up Epidemiology of Diabetes Interventions and Complications Trial (EDIC) demonstrated that adherence to these multiple diabetes management tasks is critical to achievement of lower hemoglobin A1C (A1C) levels and reduction of diabetes complications (Nathan et al., 2005; Nathan et al., 1993).

Recent evidence suggests that emerging adults (ages 18-29) with T1D are a specific group that experiences worse glycemic control, more frequent severe hypoglycemia and more frequent diabetic ketoacidosis (DKA) than any other age group (Foster et al., 2019; Helgeson et al., 2018; McCarthy & Grey, 2018; Pettus et al., 2019; Schwandt et al., 2017). Emerging adults have the lowest uptake of diabetes technology (insulin pumps and continuous glucose monitors), which may contribute to only 15% meeting an A1C target of <7% with American youth specifically having worse glycemic control than their international counterparts (Foster et al., 2019; Hermann et al., 2020). Despite these many technological advancements in treatment and improvements in care, emerging adults are also still developing complications of diabetes, including cardiovascular disease, retinopathy and nephropathy, at a young age, increasing the risk of premature mortality (Bryden, Dunger, Mayou, Peveler, & Neil, 2003; James, Gallagher,

Dunbabin, & Perry, 2014; Rawshani et al., 2018). Additionally, psychological outcomes, including depression, anxiety and disordered eating, tend to worsen during this time period (Baucom, Turner, Tracy, Berg, & Wiebe, 2018; Johnson, Eiser, Young, Brierley, & Heller, 2013; Rassart et al., 2015).

Emerging adulthood is a unique developmental stage from ages 18-30, when youths experience multiple transitions (Arnett, 2000, 2015). Emerging adults with T1D experience all of these changes within the context of living with T1D. They become geographically distinct from their parents for the first time by moving out of their childhood home, while they start college or their first career (Peters, Laffel, & American Diabetes Association Transitions Working Group, 2011). They become increasingly financially independent and assume a greater responsibility for their own health and healthcare (Weissberg-Benchell, Wolpert, & Anderson, 2007). At the same time, friends and romantic partners become the most meaningful relationships in their lives instead of their family of origin (Ersig, 2019; Raymaekers et al., 2017). These many transitions and stressors can magnify the diabetes specific emotional burden of living with T1D.

Diabetes distress (DD) is an important construct related to the existence of multiple diabetes-specific stressors. DD is the set of negative emotions that result from living with T1D. These emotions include feeling overwhelmed, hopeless, frustrated, fearful, angry and guilty related to managing T1D (Kalra, Verma, & Balhara, 2018). These feelings can be exacerbated by a lack of understanding and support from family, friends and healthcare providers (Hagger, Hendrieckx, Sturt, Skinner, & Speight, 2016; Sturt, McCarthy, et al., 2015). DD is associated with higher A1C levels, impaired quality of life and less frequent self-management behaviors (Joensen, Tapager, & Willaing, 2013; Lerman-Garber et al., 2003). Experts believe that DD affects future health outcomes in that it contributes to impairment in one's ability to convert strongly desired self-care intentions into actions. Despite every intention to complete all of the daily diabetes management tasks, DD can make completing diabetes tasks more difficult, sometimes even impossible, contributing to poorer health outcomes (Fisher, Hessler, Polonsky, Strycker, et al., 2018; Gonzalez, Fisher, & Polonsky, 2011).

It is important to note that DD is similar to, but distinct from, depression (Fisher, Gonzalez, & Polonsky, 2014). It is not psychopathology and there is no medication to treat DD (Dennick, Sturt, & Speight, 2017). DD is embedded in the day-to-day experience of living with diabetes, as opposed to the generic feeling of depressed affect that is not tied to a specific context or experience (Skinner, Joensen, & Parkin, 2019). Additionally, DD is not a complication of T1D, instead it is the experience of normal emotions and a common part of living with T1D; however, when DD becomes elevated it can have a negative impact on health outcomes. DD has been noted to have a stronger association with higher A1C levels than depression in people living with T1D (Strandberg, Graue, Wentzel-Larsen, Peyrot, & Rokne, 2014; Strandberg et al., 2015). Furthermore, the negative effect of DD on glycemic control occurs across the lifespan, from adolescents to emerging adults and through adulthood (Balfe et al., 2013; Hagger et al., 2018; Lasaite, Dobrovolskiene, et al., 2016).

DD is a contemporary concept that first entered the clinical and research vernacular in 1995 (Skinner et al., 2019). The first measure of DD was entitled the Problem Areas in Diabetes (PAID), a 20-item measure of emotional responses to living with diabetes (Polonsky et al., 1995). Initial analyses of the PAID demonstrated high internal reliability and convergent validity, but were limited by a small sample. Since then, the PAID has been evaluated extensively, translated into many languages and has shown cross-cultural reliability (Polonsky et al., 1995; Schmitt et al., 2016; Welch, Jacobson, & Polonsky, 1997). In reaction to some of the limitations of the PAID, in particular the desire to include diabetes provider-related and interpersonal distress, Polonsky et al. (2005) designed a new measure called the Diabetes Distress Scale (DDS). The DDS is a 17-item measure with four *a-priori* distress-related domain subscales, including "emotional burden," "regimen-related distress," "physician-related distress," and "interpersonal distress." Using a more diverse sample, the DDS demonstrated good internal reliability and a factor structure that supported the subscales as designed (Polonsky et al., 2005).

In recognition of adolescents' unique experience with T1D, the PAID-Teen version was developed in 2011 to capture the emotional burden associated with becoming more independent with diabetes (Weissberg-Benchell & Antisdel-Lomaglio, 2011). This 26-item measure was recently reduced to 14 items with a corresponding measure of parental DD, both of which demonstrated good internal reliability and convergent validity (Shapiro et al., 2018). Additionally, younger children experience the emotional work of living with T1D slightly differently, so the PAID-Peds was developed in 2000 and revised in 2012 to recognize this specific developmental context (Antisdel, 2000; J. Markowitz, Volkening, Butler, & Laffel, 2015), along with a corresponding measure of parental DD (J. Markowitz et al., 2012). Both of these measures demonstrated good internal validity and reliability, but were evaluated in a sample including a wide range of ages, from 8-17 years. Recognizing that the developmental context of DD may be different across this age range, a new measure of child-specific diabetes distress was developed in 2019 and was evaluated in sample ranging from 8-12 years; a corresponding measure of parental DD was included (Evans et al., 2019).

So it is clear that researchers and clinicians have long recognized the effect of developmental context on the experience of living with T1D and thus developed measures that capture those varied emotional experiences. Yet, the developmental context of emerging

adulthood presents different challenges, burdens and emotional work when managing T1D (Balfe et al., 2013). This age group has diabetes-related emotions that overlap and are similar to other age groups; however, the developmental context of emerging adulthood presents many additional and unique emotional burdens of living with T1D.

Numerous studies have described the developmental challenges specific to living with T1D during this life stage. For example, the risk-taking behaviors that are common in emerging adulthood affect diabetes and interpersonal interactions, such as a worry about hypoglycemia with social alcohol use or body image concerns with wearing diabetes devices during sexual activity with new partners (Carlsund & Soderberg, 2019; Ramchandani, Way, Melkus, & Sullivan-Bolyai, 2019; Saylor, Hanna, & Calamaro, 2019). Additionally, emerging adulthood is characterized by numerous transitions, forging new friendships and finding romantic partners. All of these new situations and interactions with new people also come with a worry about judgement and stigma (Abdoli, Hardy, & Hall, 2017; Calamaro, Saylor, & Hanna, 2018; Jeong, Quinn, Kim, & Martyn-Nemeth, 2018). Often these worries cause emerging adults to avoid revealing their T1D or to avoid completing diabetes tasks in public, potentially reducing opportunities for support and adherence to diabetes management tasks (Clausi & Schneider, 2017; Jeong et al., 2018; B. Markowitz et al., 2019). Feelings of isolation and loneliness have the potential to escalate during the multiple transitions that occur during this time period (Ersig, 2019; Sanders, Elliott, Norman, Johnson, & Heller, 2018). Furthermore, contemporary American emerging adults reveal an overwhelming worry about possibly losing health insurance and anxiety associated with the financial burdens of living with T1D while trying to become financially independent (Blanchette, Toly, & Wood, 2019; Blanchette et al., 2020). Additionally, explicit thinking about the future becomes more important during this time period, especially for

young women starting to think about pregnancy (Abdoli et al., 2017; Fredette, Mawn, Hood, & Fain, 2016). The emotional burden of living with T1D in emerging adults is complex and embedded within the developmental context. It is critically important to ensure that measures are sufficiently sensitive to this developmental context so that the full extent of the experience of DD can be captured.

There is recent evidence that inappropriate or inadequate assessment may occur when using known, validated measures of DD developed for adults with the emerging adult population. Quinn et al. (2016) completed retrospective chart reviews of emerging adults transitioning to adult diabetes care and compared elevated DD documented as a problem by the provider to DD identified by screening with the DDS. The authors reported providers documented DD in eight of the 42 participants. Yet, the DDS screening was positive for clinically significant distress for only two of those participants. Thus, 75% of the patients with provider identified DD were not captured through the DDS screening. The authors attributed these results to a time lapse between the chart review and the DDS screening, concluding that DD must have resolved in these participants by starting therapy or medication. Notably, the authors did not recognize this finding as a possible limitation of the DDS measure in this population. Yet, this small study contributes to growing evidence that the known measures of DD may not be sensitive enough to DD within the developmental context of emerging adulthood.

For many years, emerging adults with T1D have been combined with adults or adolescents in research studies, despite their distinct developmental differences. Recently, when emerging adults have been examined separately, a grim picture has emerged. Emerging adults appear to struggle with the burden of T1D management and have worse health and psychosocial outcomes than their adult counterparts. It is time to fully recognize this developmental stage as distinct with its own unique opportunities and challenges. In line with this objective, it is critical to design measures specific for this age group while recognizing the developmentally embedded diabetes-specific stressors present during this life stage.

Theoretical Framework

The theoretical framework supporting this program of research is the developmental stage theory of emerging adulthood (Arnett, 2000, 2015). Developmental stage theory provides the context to understand how life stage influences the emotional experience of living with T1D (See Figure 1). This theoretical context has long informed the treatment of children, adolescents and adults, however emerging adults have traditionally been excluded from stage theory. Effectively, the important years of emerging adulthood have been obfuscated by the long standing schism between pediatric and adult healthcare and research, leaving them lost in between worlds (Tanner, 2006).

Arnett (2015) described the five distinguishing features of emerging adulthood: 1) *identity exploration* is not complete at the end of adolescence but instead, identity continues to be relationally defined and ultimately consolidates during this developmental stage; 2) *instability* refers to the many demographic changes (moving, college, workforce) as well as multiple revisions to the life plan during this stage; 3) *intense self-focus* is the work of learning selfsufficiency, but with it comes the burden of an increasing number of independent, self-focused decisions; 4) *feeling in-between* refers to feeling not quite an adolescent, not quite an adult, instead feeling somewhere in-between; 5) *possibilities/optimism* speaks of the first time in life when it feels as if many futures are possible and there is the potential to change the direction of one's life. These five features provide a cross-sectional view of this developmental stage and clarify the unique social and emotional challenges of emerging adulthood.

Though these five defining features can be seen across the population of emerging adults, the individual experiences during this life stage can be rather heterogeneous. Therefore, it is important to clarify that this is one developmental stage, with many paths, comprised of five defining features. This heterogeneity of experiences had led some to argue this is not, in fact, a stage, but rather a process (Arnett, Kloep, Hendry, & Tanner, 2011). However, if we take these varied experiences as context dependent, it remains clear that this developmental context is not the same context experienced by adolescents or adults. Emerging adults are unique, even if this context may not be entirely universal or immutable. And knowledge of this developmental context are context is critical to understanding the experience of the emotional burden of living with T1D.

It is important to note that mental health and mental illness are adevelopmental, in that the experience of psychopathology has defining features that are mostly consistent across the lifespan. However, DD is emotional burden within a specific context, and again this differentiates it from depression and anxiety. DD exists within the current cultural moment; this means that for young people ages 18-29 living with T1D in industrialized societies, they tend to experience multiple normative shifts during a more delayed transition to adulthood than did their parents. This is a time when young people postpone marriage and children to explore romantic relationships, pursue higher education and experience new living situations as they become independent adults separate from their family of origin (Arnett, 2000). In fact, emerging adulthood represents the years when the most significant events of people's lives tend to occur, such as finding a life partner and starting a career. All of these turning points, and ultimately the transition to traditional adult roles, profoundly influences the emotional experience of living with T1D during this time period. Thus, it remains vitally important to capture this emotional burden within the developmental context of the stage theory of emerging adulthood.



Figure 1. Conceptual map of how developmental stage theory affects diabetes distress

Purpose of the Study

The emotional burden of living with T1D is unique in emerging adulthood and evidence suggests that existing measures may not accurately capture the depth and complexity of this experience. Also, despite advancing technologies and treatments, emerging adults are not meeting glycemic targets, are developing diabetes complications and are experiencing worse psychological outcomes. However, the exact cause of this deterioration is not clear. DD is an important construct and is linked with numerous poor outcomes across age groups. Therefore, it is paramount to create a measure of DD specific to emerging adulthood to more fully understand the link between DD and outcomes during this developmental stage in order to move the science in this area forward. Therefore, the overall question driving this program of research is: How do the challenges of emerging adulthood inform our understanding of DD? And the overall purpose of this program of research is to develop and validate a new measure of DD for use with emerging adults.

To accomplish this purpose, three specific aims have been proposed and addressed in three manuscripts, which collectively form a body of work that progresses in a step-wise fashion (Table 1). The first manuscript (Aim 1) describes the gap in the literature by revealing that qualitative studies demonstrate a complex and multifaceted emotional experience in emerging adults with T1D. The second manuscript (Aim 2) reduces and refines a new measure of DD, entitled the Problem Areas in Diabetes—Emerging Adult version (PAID-EA) using Rasch analysis. And the third manuscript (Aim 3) is a psychometric validation using classical test theory of the PAID-EA, as well as testing for associations with related constructs and clinical variables.

Table 1.

Overall purpose and specific aims

Aim	Hypothesis	Chapter
of diabetes distress (DD).		
Overall Purpose: Explore how the	challenges of emerging add	ulthood inform our understanding

Aim	Hypothesis	Chapter
<u>Aim 1:</u> Describe how emerging adulthood impacts DD through an integrative review of both quantitative and qualitative studies.	DD is highly prevalent in emerging adults but is more complex and developmental stage specific than may be captured in current measures.	<u>Chapter 2:</u> Wentzell, K., Vessey, J. A., & Laffel, L. M. B. (2020). How do the challenges of emerging adulthood inform our understanding of diabetes distress? An integrative review. <i>Current Diabetes</i> <i>Reports, 20</i> (6), 21.
<u>Aim 2:</u> Develop, reduce and refine a new developmentally appropriate measure of DD in emerging adults entitled the Problem Areas in Diabetes- Emerging Adult (PAID-EA).	The reduced and refined PAID-EA fits the Rasch Model.	<u>Chapter 3:</u> Wentzell, K., Vessey, J. A., Laffel, L., & Ludlow, L. (2020). Diabetes distress in Emerging Adults: Refining the Problem Areas in DiabetesEmerging Adult version using Rasch Analysis. <i>Journal of Applied</i> <i>Measurement, 21</i> (4), 481-495.
<u>Aim 3:</u> Test and validate the PAID-EA using classical test theory approaches and assess associations with related constructs.	The PAID-EA is a psychometrically valid measure of DD in emerging adults and is correlated with related constructs.	<u>Chapter 4:</u> Assessing Diabetes Distress in Emerging Adults: Development and Validation of the Problem Areas in Diabetes—Emerging Adult Version
		dissertation defense.

It is important to note that each aim and chapter builds on the prior work, such that each

piece is a critical component of this body of research. The integrative review (Chapter 2)

identifies the gap in knowledge by exploring how the specific challenges of emerging adulthood influence the experience of diabetes distress, concluding with a statement on the need to develop a measure that recognizes the impact of this developmental stage on the emotional burden of T1D. The Rasch analysis (Chapter 3) is the initial psychometric evaluation of the PAID-EA and concludes with the introduction of a new developmentally-specific measure that would benefit from additional psychometric evaluation. Finally, the classical test theory-based psychometric validation of the refined PAID-EA (Chapter 4) confirms the reliability and validity of the new measure in preparation for clinical and research use.

Implications for Nursing Research and Practice

This program of research has the potential to substantively forward our understanding of the emotional burden of living with T1D as an emerging adult by being able to measure it, within this developmental context, for the first time. It is important to recall that accurate measurement of variables is the foundation of all of empirics. Thus, it is critical to develop measures that reliably and validly measure the constructs of interest for use in both research and clinical practice. If the developmentally embedded emotional work of living with T1D during emerging adulthood is not measured accurately, there remains little hope of understanding why this age group experiences worse outcomes than other age groups. Currently, the known measures of DD do not capture the developmental hurdles, the multiple transitions and the feelings of uncertainty that define the experience of living with T1D during this time period. As a result, the current measures may underestimate DD in emerging adults as they are not sufficiently sensitive to the worries and frustrations that are specific to emerging adulthood. Ultimately, this underestimation could hinder the capacity to observe and test for associations with A1C levels, adherence to diabetes management tasks and other outcomes. Thus, it is critical to be able to accurately

capture and describe the emotional work of T1D during emerging adulthood so that researchers can proceed to the next important step of designing interventions to improve outcomes.

Additionally, this program of research highlights the limitations of the current organization of clinical care delivery, which does not recognize emerging adulthood as a distinct developmental stage and does little to facilitate the provision of quality care for those often lost in between the pediatric and adult world (Anderson & Wolpert, 2004; Hanna, Scott, & Schmidt, 2014). There has been extensive research on the transition from pediatric diabetes care to adult diabetes care with little consensus on how exactly to do it successfully (Saylor, Boyle, Buck, Bean, & Aurele, 2015; Schultz & Smaldone, 2017). Yet taking a developmental perspective that breaks down the schism between pediatric and adult healthcare to provide emerging adults grounding in a healthcare home that understands them is an important way to begin to address the unique emotional burden of living with T1D during this life stage (Kullgren, McLaughlin, Mitra, & Armstrong, 2012; Wagner, Ulrich, Guttmann-Bauman, & Duke, 2015). It has been noted that clinical providers that simply recognize the developmentally embedded emotional burden within a clinic visit can have a profound impact on these patients and can be a critical support system to help reduce DD in emerging adults (Calamaro et al., 2018; Carlsund & Soderberg, 2019; Hilliard et al., 2018; Patel, Datye, & Jaser, 2018; Ramchandani et al., 2019). So, by designing a measure of DD in emerging adults, the developmentally-embedded emotional burden of T1D as DD can be centered within the clinical conversation, so that DD can be highlighted and prioritized, but also so that DD can be measured and tied to outcomes. This program of research moves this clinical conversation forward to ensure quality diabetes care for emerging adults living with the emotional burden of T1D.

Summary

21

The collective body of work set forth in this dissertation addresses the gap in our ability to measure of DD within the developmental context of emerging adulthood. A reliable and valid measure of DD for emerging adults pushes science in this area forward and advances clinical care.

Chapter 2

How do the challenges of emerging adulthood inform our understanding of diabetes distress? An integrative review

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This manuscript represents a significant contribution to the Dissertation work and represents portions of the background and significance of the traditional dissertation. Ms. Wentzell is the primary author and Dr. Vessey is the senior author. This manuscript is published in Current Diabetes Reports. Current Diabetes Reports is an indexed and peer-reviewed journal with an impact factor of 4.213. Current Diabetes Reports provides in-depth review articles contributed by international experts on the most significant developments in the field. By presenting clear, insightful, balanced reviews that emphasize recently published papers of major importance, the journal elucidates current and emerging approaches to the diagnosis, treatment, management, and prevention of diabetes. This manuscript is in its final state. License in Appendix C.

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Abstract

Purpose: Emerging adulthood (ages 18-29) presents many emotional, social and developmental challenges that can contribute to an increased sense of burden when managing type 1 diabetes (T1D). Diabetes distress (DD) is the concept that captures the emotional burden, frustrations and worries resulting from living with T1D. This integrative review set out to examine the impact of developmental context by answering this question: How do the challenges of emerging adulthood inform our understanding of DD?

Recent Findings: DD is highly prevalent in emerging adults and occurs at higher rates than in other age groups. Qualitative studies reveal that DD is embedded within the developmental challenges specific to living with T1D during this stage.

Summary: Quantitative studies reveal the prevalence and correlates of DD in this age group, and qualitative studies augment these findings by capturing the scope and complexity of the emotional burden of living with T1D as an emerging adult.

Keywords: Type 1 diabetes, Young adults, Emerging adulthood, Diabetes distress, Integrative review

Introduction

Mounting evidence suggests that emerging adults with type 1 diabetes (T1D) are a group that experiences worse glycemic control, more frequent severe hypoglycemia and more frequent diabetic ketoacidosis (DKA) than any other age group (Foster et al., 2019; Helgeson et al., 2018; McCarthy & Grey, 2018; Pettus et al., 2019; Schwandt et al., 2017). Also, there is a significant worsening of both diabetes complications and psychological outcomes during this time period (Baucom et al., 2018; Berg et al., 2018; Bryden et al., 2003; Northam, Lin, Finch, Werther, & Cameron, 2010). Emerging adulthood is a unique developmental period from ages 18-29, when youths with T1D are at the cusp of multiple transitions; as a result, they experience high levels of uncertainty (Arnett, 2015; Monaghan, Helgeson, & Wiebe, 2015; Peters et al., 2011). During this period, they often move out of their parent's home and enter college or the workforce. Emerging adults become increasingly financially independent and bear a greater responsibility for decisionmaking and their own healthcare. Additionally, this is the time when people with T1D transition from pediatric to adult diabetes care. Simultaneously, relationships with friends and romantic partners become more important, and responsibility for diabetes management shifts away from their parents and family members. Collectively, these multiple changes and stressors can compound the diabetes specific emotional burden of living with T1D.

Diabetes distress (DD) is an important construct related to these developmentally embedded, diabetes-specific stressors of emerging adulthood. DD refers to the negative emotions that result from living with T1D (Fisher et al., 2014). These emotions include feeling frustrated, hopeless, overwhelmed, angry, fearful and guilty related to managing T1D (Kalra et al., 2018), which can be exacerbated by a lack of support and understanding from friends, family and healthcare providers (Hagger et al., 2016; Sturt, Dennick, Due-Christensen, & McCarthy, 2015). DD affects health outcomes by contributing to an individual being unable to convert strongly desired self-care intentions into actions; in that, despite every intention to complete all of the daily diabetes management tasks, DD can make it harder, sometimes even impossible, to complete all of the tasks that contribute to positive health outcomes (Fisher, Hessler, Polonsky, Strycker, et al., 2018; Gonzalez et al., 2011).

DD is increasingly considered one of the most important psychosocial concerns in the care of people with T1D. DD affects over 40% of all individuals with diabetes (Nicolucci et al., 2013) and has been associated with higher hemoglobin A1C (A1C) levels, impaired quality of life and less frequent self-management behaviors (Joensen et al., 2013; Lerman-Garber et al., 2003). The negative effect of DD on glycemic control is seen across the lifespan, from children, adolescents and then to adults (Dennick et al., 2017; Hagger et al., 2016). Given its clinical importance, a recent international consensus study recommended that DD should be a core clinical outcome measured in future intervention studies conducted with emerging adults (Byrne et al., 2017). Therefore, this integrative review sets out to examine the impact of this developmental context by answering this question: How do the challenges of emerging adulthood inform our understanding of DD?

Methods

Literature Search

The search was conducted through CINAHL, Pubmed and PsycINFO electronic databases. A combination of keywords was used to define the population: *type 1 diabetes AND emerging adult* OR young adult** and to define the outcome: *diabetes distress OR burden OR emotion* OR "quality of life" OR "psychological distress" OR depression.* The search was limited to publications since 2015 to reflect the most recent research on the emotional work of

living with T1D within a developmental context that is informed by an ever-changing culture,

the increasing use of diabetes technologies and a shifting healthcare marketplace.

Studies were eligible for inclusion if:

- a. The sample included emerging adults (defined as ages 18-29 years, based off the broadest definition from Arnett (2015)) with T1D. Studies of larger age ranges were included only if analyses of DD were age stratified and results were reported separately for participants ages 18-29 years.
- b. They were cross-sectional, observational, experimental, quasi-experimental or qualitative studies.
- c. They were published in a peer-reviewed English language journal and were conducted in a Westernized society.

Results

Study Selection and Quality Appraisal

Many articles met the initial criteria for inclusion, but were ultimately excluded because the measures of distress were not full measures of DD or were a combination of measures to create a proxy for DD. In order to make appropriate comparisons across studies, studies were included only if the authors used validated, full measures of DD as delineated by Dennick at al. (Dennick et al., 2017) and the authors reported mean or median DD scores or prevalence of elevated DD. The two measures of DD included are the Problem Areas in Diabetes (PAID, a 20-item measure, scores of each item are summed, then multiplied by 1.25 to generate a total score of 0-100, higher scores indicate greater distress) (Polonsky et al., 1995) and the Diabetes Distress Scale (DDS, a 17-item measure, scores of each item are averaged, higher scores indicate greater distress) (Polonsky et al., 2005). Both the PAID and DDS have clinical cut points to define

elevated DD. The PAID's initial validation created a cutoff of ≥ 40 (Snoek, Bremmer, & Hermanns, 2015; Welch et al., 1997; Welch, Weinger, Anderson, & Polonsky, 2003), and more recently, Hermanns et al. used receiver operating characteristic curve analysis to determine a cut off of ≥ 33 for clinically significant distress (2006). This review will define DD scores on the PAID ≥ 40 as elevated DD and scores of 33-39 as moderate (possibly clinically significant) DD. The DDS has suggested cut points of <2.0: little to no distress; 2.0-2.9: moderate distress; and \geq 3.0: elevated distress (Fisher, Hessler, Polonsky, & Mullan, 2012).

All qualitative studies in this review examined the emotional burden of living with T1D, which included emotions, frustrations and diabetes-specific stressors; however, no authors used the specific term "diabetes distress." Only one qualitative study was identified that explored DD named as such in emerging adults and it was excluded from this review because it was published in 2013, which is outside of the inclusion window (Balfe et al., 2013). Therefore, all qualitative studies that explored the emotional burden of living with T1D as an emerging adult were included.

Ultimately, 11 quantitative (four intervention studies) and 11 qualitative studies were retained. Details of these quantitative and qualitative studies are presented in Tables 1 and 2. It is important to note that the quantitative studies included inform our understanding of prevalence and severity of DD and its associations with glycemic and other psychosocial outcomes, but these studies provide little reflection on how the challenges specific to the developmental context of emerging adulthood inform our understanding of the emotional burden of living with T1D. In this integrative review, quantitative studies provide important background evidence of DD in larger, more representative samples, while the qualitative studies offer the developmental reflection on the impact of emerging adulthood on the experience of DD.

Study Characteristics

Sample sizes in quantitative studies varied enormously (n = 20-602) and the mean age of participants varied as well (17.9 to 26.8 years). Of the 11 studies, five were conducted in the USA (Albanese-O'Neill et al., 2018; Bakhach et al., 2019; Garvey et al., 2017; Quinn et al., 2016; Tanenbaum et al., 2017), and one each in Canada (Spaic et al., 2019), Denmark (Zoffmann, Vistisen, & Due-Christensen, 2015), Germany (Stahl-Pehe et al., 2019), Australia (Downie, Mullan, Boyes, & McEvoy, 2019) and Lithuania (Lasaite, Ostrauskas, Zalinkevicius, Jurgeviciene, & Radzeviciene, 2016). One study was transnational (Vallis, Willaing, & Holt, 2018). Most studies recruited from diabetes clinics, but five recruited from national registries (Garvey et al., 2017; Lasaite, Ostrauskas, et al., 2016; Stahl-Pehe et al., 2019; Tanenbaum et al., 2017; Vallis et al., 2018). Three studies were focused on the transition from pediatric care to adult care (Garvey et al., 2017; Quinn et al., 2016; Spaic et al., 2019). One study recruited only participants with poorly controlled T1D (Zoffmann et al., 2015). One study recruited participants with early-onset diabetes (age 0-4) (Stahl-Pehe et al., 2019). Only two studies were randomized controlled trials (Spaic et al., 2019; Zoffmann et al., 2015). One study (Vallis et al., 2018) used a validated abbreviated measure of DD: the PAID-5 (McGuire et al., 2010). Two studies used translated versions of the PAID: one into Lithuanian (Lasaite, Ostrauskas, et al., 2016) and one into Danish (Zoffmann et al., 2015). Both translations were consistent with standardized instrument translation techniques.

Of the 11 qualitative studies, seven were conducted in the USA (Abdoli et al., 2017; Calamaro et al., 2018; Ersig, 2019; Fredette et al., 2016; Jeong et al., 2018; Ramchandani et al., 2019; Saylor et al., 2019), two were conducted in Canada (Clausi & Schneider, 2017; B. Markowitz et al., 2019) and one each in the UK (Sanders et al., 2018) and Sweden (Carlsund & Soderberg, 2019). Four studies recruited participants from a college-based peer support groups (Calamaro et al., 2018; Ersig, 2019; Fredette et al., 2016; Saylor et al., 2019). Some studies targeted specific subgroups of emerging adults: two studies report different results from one sample of emerging adults that were diagnosed with T1D as an emerging adult (Calamaro et al., 2018; Saylor et al., 2019), one study focused on emerging adults living in rural Appalachia (Abdoli et al., 2017) and one study explored the experience of young women with T1D (Clausi & Schneider, 2017).

Background Evidence of DD

Prevalence and severity of DD. The mean DD scores \pm standard deviation and/or median and/or prevalence percentages of elevated DD are shown in Table 1. These quantitative studies reveal that DD is highly prevalent and severe in emerging adults. Of the five studies that described prevalence of DD, almost all reported clinically concerning rates of DD in emerging adult samples; 27.9% (PAID \geq 40) (Lasaite, Ostrauskas, et al., 2016), 49.1% (PAID \geq 40) (Downie et al., 2019), and 60.1% (PAID-5, recoded to scores 0-100, \geq 40) (Vallis et al., 2018). The one study that had a much lower prevalence of elevated DD scores was a sample of emerging adults that were diagnosed at a very young age who likely had a different experience with T1D. In this study, rates varied from 12.2%, to 13.9% to 16.4% among different samples (used PAID \geq 40) (Stahl-Pehe et al., 2019). The severity of DD is particularly clinically concerning; of the nine studies that reported mean DD scores, most studies had a mean score classified as moderate or elevated (Bakhach et al., 2019; Downie et al., 2019; Spaic et al., 2019; Tanenbaum et al., 2017; Vallis et al., 2018; Zoffmann et al., 2015). Of note, the only transnational study included in this review had a mean DD score classified as elevated (Vallis et al., 2018). Five studies had a moderate mean DD score for the entire sample or in at least one

group studied (Bakhach et al., 2019; Downie et al., 2019; Spaic et al., 2019; Tanenbaum et al., 2017; Zoffmann et al., 2015). Only two studies reported mean DD scores below the clinically significant cutoff (Albanese-O'Neill et al., 2018; Garvey et al., 2017). One study only reported low median levels of DD and did not report mean scores (Lasaite, Ostrauskas, et al., 2016).

Of note, Quinn et al. completed retrospective chart reviews and compared elevated DD documented as a problem by the provider to self-reported DD identified by screening with the DDS (2016). The authors found that 2/42 participants had elevated DD noted by the provider in the chart and on the DDS screening, 1/42 participants had no DD noted by the provider in the chart but had elevated DD on the DDS screening and 6/42 participants had elevated DD noted by the provider in the provider in the chart, but they did not have elevated DD on the DDS screening. This finding is important as it may speak to the limitations of DD measures within the developmental context of emerging adulthood.

DD and demographic characteristics. Based on findings from these studies, DD appears to be more severe in emerging adults compared to other age groups. For example, one study reported that emerging adults reported higher DD than adolescents within gender; a significant difference in median PAID scores was observed between male adolescents and male emerging adults (p = .002) and female adolescents and female emerging adults (p = .016) (Lasaite, Ostrauskas, et al., 2016). Two studies reported emerging adults had significantly more DD compared to older adults (p < .001) (Tanenbaum et al., 2017) and (p = .001) (Vallis et al., 2018). Also, one study stratified emerging adults by older and younger; older emerging adults (25-30 years old) had significantly higher DD than younger ones (18-24 years old) (p = .017) (Vallis et al., 2018).

The relationship between DD and gender in emerging adults is not clear. One study

reported a significant association between higher DD and female gender (p < .001) (Stahl-Pehe et al., 2019). Another study found a similar pattern in the entire study sample (age 18-80), but DD by gender was not discussed by age strata, so it is unclear if this pattern holds in just emerging adults (Tanenbaum et al., 2017). Additionally, the study described in the above paragraph compared median PAID scores by gender and found no significant difference in overall PAID scores between emerging adult males and females by age category, but identified that females had a significantly higher score on the PAID negative emotional consequences subscale (p < .05) (Lasaite, Ostrauskas, et al., 2016). Of note, only one study examined associations with DD and socioeconomic status and found that lower DD was associated with higher socioeconomic status (p = .002) (Stahl-Pehe et al., 2019). Overall, it appears that DD is more severe in emerging adults compared to other age groups and the relationship to gender needs further investigation.

DD and clinical characteristics. DD may play a role in clinical outcomes and diabetes management tasks in emerging adults. Almost all studies collected A1C data, however only two studies compared A1C and DD; one study found a significant positive correlation between DD and A1C in both cross-sectional and longitudinal cohorts (p = .005) (Stahl-Pehe et al., 2019) and another study reported no significant association (p not reported) (Lasaite, Ostrauskas, et al., 2016). DD may impact diabetes management behaviors; one study found that increased DD was associated with less frequent blood glucose monitoring (p < .01) (Downie et al., 2019) and another study used a path analysis to describe a direct negative association between DD and blood glucose monitoring behaviors ($p \leq .01$) One study found that higher DD was significantly associated with longer diabetes duration (p < .05) (Lasaite, Ostrauskas, et al., 2016). One study found higher DD was associated with low satisfaction with treatment (p < .001) and lower DD was associated with better self-reported health outcomes (p < .001) (Stahl-Pehe et al., 2019). Despite the fact that almost all studies collected A1C data, there remains a need to further clarify the relationship between DD and glycemic control in emerging adults. Additionally, DD may have an indirect impact on glycemic control through its influence on diabetes management behaviors.

DD and psychosocial outcomes. DD may influence the emotional and psychosocial experience of living with T1D. Four studies included measures of depressive symptoms (Bakhach et al., 2019; Downie et al., 2019; Quinn et al., 2016; Vallis et al., 2018), however only one study reported associations between DD and depression and found that higher DD was associated with depression in emerging adults (p < .001) (Stahl-Pehe et al., 2019). Interestingly, one study noted that in those emerging adults that have already transitioned to an adult provider, feeling prepared for the transition was significantly associated with lower DD (p = .02) (Garvey et al., 2017). In conclusion, many authors included measures of depressive symptoms, but the specific association of depression with DD in emerging adults needs further study.

DD in intervention studies. Four studies included in this review were intervention studies, all of which provided emerging adults with additional support. One study was a brief pilot feasibility study using a web-based education and support intervention. In this study, mean levels of DD were reduced, but this finding was not statistically significant (p = .09) (Albanese-O'Neill et al., 2018). Another study examined psychosocial outcomes from a shared medical appointment and telemedicine intervention and found DD was significantly reduced after 1 year (p = .03) (Bakhach et al., 2019). Two studies were randomized controlled trials (RCT). One RCT evaluated effectiveness of a structured transition program with an 18-month intervention and a 12-month follow-up. DD was significantly reduced in the intervention group immediately post intervention (p = .049), however that reduction was not sustained at 12-month follow-up (p = .642) (Spaic et al., 2019). One RCT utilized both group and individual nurse-led guided selfdetermination sessions using reflection sheets to develop life skills; it showed a significant reduction in DD in the intervention group and among female participants in both groups (p < .001). Male participants did not report a significant reduction in DD (p not reported) (Zoffmann et al., 2015). Notably, none of these interventions specifically targeted DD and none of the studies had DD as the primary endpoint. Despite the lack of focus on DD, participants in all of the interventions reported reductions in DD and three of the interventions reduced DD significantly. This reduction in DD is likely a result of the interventions targeting social and emotional support, which consequently improved DD

Summary of the background on DD. From the quantitative studies, it is clear that DD is highly prevalent and occurs at clinically significant levels in emerging adults. DD appears to occur at higher rates in emerging adults than in other age groups, and there is emerging evidence that it may be associated with many of the same clinical and psychosocial outcomes as have been demonstrated in other populations (i.e., female gender, lower SES, higher A1C, people experiencing depression). Though none of the interventions reviewed specifically targeted DD, all of the intervention studies reported reduced DD in emerging adults.

DD within the Developmental Context of Emerging Adulthood

The qualitative studies reviewed provide great insight into the emotional experience of young adults, despite neither the authors nor the participants naming DD specifically. The authors describe a range of themes related to the frustrations and worries of living with T1D as an emerging adult. This variety of emotional burden defines DD but was described by the authors using a number of different terms. The themes that were common among a majority of

the studies will be discussed as they relate to the burden of living with T1D as an emerging adult and inform the understanding of the complexity and uniqueness of this developmental period. Three overarching themes were identified by the authors of this review upon careful reflection on the underlying subthemes. All subthemes were identified by the authors of the original articles.

Externally-focused frustrations. The first theme identified was "Externally-focused frustrations" and it occurred in all studies. This theme related to externally-focused irritations and annoyances both big and small. It was comprised of three subthemes: the emotional burden related to stigma, the effort of having to plan ahead and feelings of not being understood. The burden of stigma (the experience of negative feelings, including rejection or blame, due to the perceived stigma of having diabetes) was identified in 8 of the 11 studies (Abdoli et al., 2017; Calamaro et al., 2018; Carlsund & Soderberg, 2019; Clausi & Schneider, 2017; Jeong et al., 2018; B. Markowitz et al., 2019; Ramchandani et al., 2019; Sanders et al., 2018; Saylor et al., 2019). This frustration of stigma reflects the emotional work that is related to others' perceptions. Most studies identified how stigma made it harder to complete diabetes tasks (Carlsund & Soderberg, 2019; Clausi & Schneider, 2017; Jeong et al., 2018; B. Markowitz et al., 2019; Ramchandani et al., 2019; Sanders et al., 2018) and participants identified that the experience of stigma resulted in the need to educate others about T1D, which was burdensome (Abdoli et al., 2017; Carlsund & Soderberg, 2019; Clausi & Schneider, 2017; Jeong et al., 2018; Ramchandani et al., 2019). The effort required for constant planning was identified in 7 of the 11 studies (Carlsund & Soderberg, 2019; Clausi & Schneider, 2017; Fredette et al., 2016; Jeong et al., 2018; B. Markowitz et al., 2019; Ramchandani et al., 2019; Saylor et al., 2019). This frustration involved always thinking ahead about food, activity, stress, illness as well as having to carry devices and supplies. Emerging adults identified this work as being overwhelming,

tiresome and "just adds a really extra thick layer to everything" (p. 76) (Saylor et al., 2019). The burden and associated frustration of these tasks was unique to emerging adults' developmental stage, where their experiences are often understood as a reflection of other's experiences, such that their peers did not have this additional work. As a result, they felt more isolated (Clausi & Schneider, 2017; Jeong et al., 2018; B. Markowitz et al., 2019; Ramchandani et al., 2019). This work was also related to emerging adults becoming newly and completely independent with diabetes management, in contrast to adolescence (Abdoli et al., 2017; Fredette et al., 2016; B. Markowitz et al., 2019). Frustrations associated with feelings of not being understood by their peers because of diabetes were identified in 7 of the 11 studies (Abdoli et al., 2017; Carlsund & Soderberg, 2019; Clausi & Schneider, 2017; Ersig, 2019; Jeong et al., 2018; B. Markowitz et al., 2019; Sanders et al., 2018). Emerging adults identified that when they did not feel that others understood them, they felt different or abnormal, which contributed to them feeling isolated. This frustration was particularly relevant to emerging adults, as identity continues to be relational and connections to others are a priority during this developmental stage. Overall, "externally-focused frustrations" represent how emerging adults view themselves in the world and in relation to others, and because of diabetes, they ultimately feel burdened, overwhelmed and isolated.

Internally-focused worries. The second theme identified was diabetes specific "Internally-focused worries" and it was represented in 8 of 11 studies (Abdoli et al., 2017; Calamaro et al., 2018; Carlsund & Soderberg, 2019; Clausi & Schneider, 2017; Ersig, 2019; Fredette et al., 2016; Ramchandani et al., 2019; Saylor et al., 2019). These included concerns and fears that resulted from living with T1D as an emerging adult. This theme was comprised of four specific subthemes: fear of hypoglycemia, worry about drinking alcohol, concerns about financial costs and uncertainty about future health. Fear of hypoglycemia was identified in 4 of
the 8 studies (Abdoli et al., 2017; Carlsund & Soderberg, 2019; Clausi & Schneider, 2017; Ramchandani et al., 2019). Participants in these studies described that this fear of hypoglycemia contributed to intentionally maintaining higher than target blood glucose levels. This worry also contributed to emerging adults, especially females, feeling that they needed to be more cautious than their peers (Clausi & Schneider, 2017; Ramchandani et al., 2019). Worry about drinking alcohol was identified in 3 of the 8 studies (Carlsund & Soderberg, 2019; Ramchandani et al., 2019; Saylor et al., 2019), specifically the concern about hypoglycemia with alcohol and its potential impact on socializing with peers. Worry about the financial cost of diabetes was reported in 2 of the 8 studies (Abdoli et al., 2017; Ersig, 2019). Both studies identified participants' worries related to being able to afford diabetes supplies while working towards being financially independent and living on their own. Finally, the theme of uncertainty about future health was identified in 3 of the 8 studies (Calamaro et al., 2018; Ersig, 2019; Fredette et al., 2016). Though this worry can occur at any age, emerging adults are becoming more concrete in their future thinking during this developmental stage and are less likely to feel invincible. In particular, the worry about the risk of future complications and, in females, the worry about having a healthy pregnancy became more salient and overwhelming during this stage. Participants explained that complications felt inevitable despite their effort and, for many participants, the worry about them was all-consuming (Calamaro et al., 2018; Ersig, 2019; Fredette et al., 2016). Generally, "internally-focused worries" encompass the subjective concerns and fears about living with T1D that consumes the emotional energy of emerging adults.

Changes. The third theme identified was "Changes" and it was observed in all studies. Changes reflect the many transitions that emerging adults experience and the effect of these transitions on the emotional burden of living with T1D. This theme was comprised of three subthemes: evolving identity as a person with T1D, changing support networks, and new relationships with healthcare providers. Evolving identity as a person with T1D was expressed in 6 of the 11 studies (Clausi & Schneider, 2017; Fredette et al., 2016; Jeong et al., 2018; B. Markowitz et al., 2019; Ramchandani et al., 2019; Saylor et al., 2019). Identity as a person with T1D continues to emerge within the developmental context of emerging adulthood, supporting the developmental principle that identity is complex and continually evolving. Most participants described diabetes as a part of who they were but stated that it does not define them, in that "I happen to have diabetes... but that doesn't have to be who I am." (p. 490) (Ramchandani et al., 2019). Changing support networks was identified in 8 of the 11 studies (Abdoli et al., 2017; Calamaro et al., 2018; Carlsund & Soderberg, 2019; Ersig, 2019; Fredette et al., 2016; Jeong et al., 2018; Sanders et al., 2018; Saylor et al., 2019). As emerging adults transition to new situations, they develop new support networks, including peers and romantic partners. All eight of these studies identified these new support networks as critical to managing diabetes. Many participants identified having peers that also had T1D as being particularly meaningful and supportive (Abdoli et al., 2017; Calamaro et al., 2018; Fredette et al., 2016; Sanders et al., 2018). The theme of new relationships with healthcare providers was identified in 7 of the 11 studies (Abdoli et al., 2017; Calamaro et al., 2018; Carlsund & Soderberg, 2019; Jeong et al., 2018; B. Markowitz et al., 2019; Ramchandani et al., 2019; Sanders et al., 2018). These changes were primarily in the context of the emotional work of transitioning to an adult provider. Two studies specifically explored the emotional connection with pediatric providers and the search for that same connection with new adult providers (Calamaro et al., 2018; Ramchandani et al., 2019). Ultimately, it appears that the multiple transitions and changes that occur during emerging adulthood impact many aspects of living with T1D and these transitions play an important role in understanding how living with T1D during this developmental stage may be different than other life stages.

Summary of the developmental context of DD. None of the qualitative studies included in this review used the term DD explicitly, but all studies explored how the developmental context of emerging adulthood affects the emotional experience of living with T1D. The depth of the themes and subthemes represent a multifaceted portrait of the psychosocial concerns for emerging adults living with T1D.

Discussion

This integrative review revealed that the challenges of emerging adulthood greatly influence the emotional burden of living with T1D. These studies support that DD is experienced by a meaningful percentage of emerging adults and suggest that it is higher in emerging adults than in other age groups. Mounting evidence also supports that DD may be more prevalent than previously recognized, as this developmental stage presents multiple social, emotional and physical challenges that compound the management of T1D. Additionally, it is important to note that for many years, emerging adults have been combined with older adults in research studies, potentially obscuring the distinct challenges, developmentally, socially and emotionally, experienced by this age group when managing diabetes (Weissberg-Benchell et al., 2007).

The qualitative studies reviewed here reveal how the developmental context of emerging adulthood contributes to a more complex picture of burden and worries that are specific to living with T1D during emerging adulthood. For example, the stigma of diabetes may have different consequences, as emerging adults remain very aware of other's perceptions about their T1D and this will likely influence their self-care. Also, emerging adults seek meaningful connections with peers and their identity continues to be relationally defined. Therefore, when an emerging adult feels their peers do not understand life with diabetes, they may avoid social events because of diabetes worries. In this way, T1D can have a more significant impact on the developmental process of identity exploration through social connections. This developmental perspective is critical to being able to accurately describe and measure the opportunities and challenges of living with T1D as an emerging adult.

Interestingly, all of the qualitative studies in this review provided insight on the experience of DD, but did not use the term "diabetes distress." It is possible that qualitative authors avoided the term because it sits more squarely in the quantitative realm. In fact, only one qualitative study examined DD named as such in emerging adults and identified many of the same themes uncovered here (Balfe et al., 2013). Yet it is important to note that four recent qualitative studies in this review used the term "distress" (but not DD) (Carlsund & Soderberg, 2019; Jeong et al., 2018; B. Markowitz et al., 2019; Ramchandani et al., 2019), which may represent an evolving representation of the emotional experience of living with T1D and a growing realization that this emotional work is in fact DD.

Additionally, the studies in this review describe the emotional burden of T1D, but few studies used measures of depressive symptoms or discussed how this emotional burden can be associated with depression, which highlights how DD is related to, but is distinct from, depression. Only one study in this review examined the association between DD and depressive symptoms in emerging adults (Stahl-Pehe et al., 2019). Though many of the affective traits of depression overlap with DD, it is important to note that DD is not psychopathology; instead it is the emotional burden of the multiple daily management tasks of diabetes within a social and developmental context (Fisher et al., 2014; Gonzalez et al., 2011). Interestingly, recent evidence

suggests that DD may have a stronger association with glycemic and management outcomes in both adults (Hessler et al., 2017) and adolescents (Hagger et al., 2018) than depression.

Finally, interventions targeting DD have effectively improved A1C in adults with type 2 diabetes (Zagarins, Allen, Garb, & Welch, 2012), and in adults and adolescents with T1D (Fisher, Hessler, Polonsky, Masharani, et al., 2018; Jaser, Lord, Savin, Gruhn, & Rumburg, 2018), but few interventions exist to improve outcomes in emerging adults (O'Hara et al., 2017). Additionally, recent evidence suggests that adolescents with elevated DD may have chronically elevated DD and this finding can inform the trajectory of DD in emerging adults (Iturralde, Rausch, Weissberg-Benchell, & Hood, 2019). It remains important to further clarify DD as a major psychosocial concern that is developmentally embedded in the challenges of emerging adulthood.

Limitations

This review was limited to quantitative studies that used full, validated measures of DD; some other measures of distress or modified measures of DD may provide insight into the emotional burden of living with T1D, however only full, validated measures were used in this review to allow for comparison across studies.¹ Additionally, this review included only English language publications conducted in Westernized societies. Most studies did not report detailed racial or socioeconomic demographics, but in those that did, participants were majority white non-Hispanic, highly educated and had health insurance. Therefore, results included here may not be generalized to minority or low-income populations of emerging adults with T1D. Also, all but one of the non-intervention studies were limited by a cross-sectional design, so these studies were unable to show causation or direction of effects. Finally, only the two RCTs reported power analyses and no studies calculated effect sizes of relevant variables for this review.

Implications for Future Research and Practice

Many of the themes identified in the qualitative studies are not included in either the PAID or the DDS. It is possible that neither of these measures, that were developed with older adults with T1D and type 2 diabetes, accurately assess the emotional burden of DD in emerging adults. Specifically, the PAID and the DDS may fail to capture the developmental hurdles, the many layers of transition and high levels of uncertainty that characterize living with T1D during this time period. Therefore, the current measures may underestimate DD in emerging adults if they are not sufficiently sensitive to frustrations and worries in emerging adulthood, which could limit our ability to observe significant associations with A1C, diabetes management adherence and other outcomes. Thus, further research is needed to adapt measures to capture the relevant concerns for emerging adults with T1D.

Additionally, diabetes healthcare providers can be a critical support system to help reduce DD in emerging adults. Understanding the developmental context and how it impacts diabetes management during this stage is an important first step in providing accessible and effective care to emerging adults. Though novel approaches to increase access, such as telemedicine, textmessaging or web-based programs, may be helpful for some emerging adults, it is also clear that relationships, with providers, peers and others with T1D, have a continued and profound impact on emerging adults.

Finally, this integrative review clarifies that the emotional burden of living with T1D may be different in emerging adulthood than experienced by other age groups. Emerging adulthood is characterized by unique stressors and these may influence emerging adults' ability to manage diabetes. It is possible that some aspect of emerging adulthood that is not well captured in current measures contributes to difficulty in meeting glycemic targets. The emotional burden of living with T1D as an emerging adult may be the missing link.

Conclusions

Diabetes distress in emerging adults is an understudied phenomenon and evolving evidence suggests that DD occurs at higher rates and may contribute to adverse outcomes in this age group. Additionally, the qualitative studies included reveal how the developmental context of emerging adulthood may influence the emotional burden that is specific to living with T1D during this time period. This integrative review leverages both quantitative and qualitative approaches to increase our understanding of the emotional burden of living with T1D as an emerging adult and identifies gaps in our current knowledge to inform future directions in research and clinical care.

Footnote:

¹One group in Belgium examined DD in multiple studies with emerging adults, however the authors used modified versions of the PAID and did not report total DD scores, only subscales. The results of these studies could not be compared to the other measures of DD used in this review (Luyckx, Rassart, Aujoulat, Goubert, & Weets, 2016; Luyckx, Rassart, & Weets, 2015; Oris et al., 2016; Rassart et al., 2015; J. Rassart, Luyckx, Klimstra, et al., 2014; J. Rassart, Luyckx, Moons, & Weets, 2014; Raymaekers et al., 2017).

DIABETES DISTRESS IN EMERGING ADULTHOOD

Table 1.

Quantitative studies exploring diabetes distress (DD) in emerging adults

DIABETES DISTRESS IN EMERGING ADULTHOOD

		<u>l</u>	ntervention Stu	<u>idies</u>		
Author, Year, Study Design (Country)	Intervention	Participant Characteristics: mean age, mean diabetes duration / mean age at diagnosis, % male	DD Measure	DD Score (mean +/- standard deviation)	Associations with Other Outcomes	Limitations
Albanese- O'Neill A, 2018. Pre/post feasibility study (USA)	Education & support through group video conference and web	<i>n</i> = 20, age 19.2, duration 10.2, 20% male	PAID ^a	pre: 20.4 ± 15 , post: 17.2 ± 15.3 (p = .09)	n/a	Brief (8 week) feasibility study
Bakhach M, 2019. Cohort study with control group (USA)	CoYoT1 shared medical appointment & telemedicine intervention	n = 81, Intervention group: $n = 42$, age 19.8, duration 8.2, 45% male. Control group: $n = 39$, age 20.5, diabetes duration 11.7, 41% male	DDS ^b	Intervention group baseline: $2.0 \pm$ 0.9, Control group baseline: $1.9 \pm$ 0.7, Intervention group post: $1.8 \pm$ 0.7, Control group post: 2.2 ± 0.7 (<i>p</i> = .03)	Split DDS into subscales, only interpersonal distress subscale was significant post- intervention ($p = .03$)	Pilot study, not randomized
Spaic T, 2019. Randomized controlled trial (Canada)	Structured transition program with 18 month intervention, and a 12 month follow-up	n = 466, Structured transition intervention group: n = 104, age 17.9, age at diagnosis 9.4, 55% male. Control group: $n = 101$, age 17.9, age at	DDS	Intervention group baseline: 2.0 ± 0.79 , Control group baseline: $2.01 \pm .86$. Intervention group post: $1.95 \pm .76$, Control group	Split DDS into subscales, only emotional burden of diabetes subscale was significant post- intervention ($p =$.027)	Baseline mean age just below 18

		diagnosis 10.1, 47% male		post: $2.18 \pm .83$ (p = .049) Intervention group follow-up: $2.16 \pm$.9, Control group follow-up: $2.22 \pm$.94 (p = .642)	
Zoffmann V, 2015. Randomized controlled trial (Denmark)	Flexible guided self- determination intervention in poorly controlled T1D	<i>n</i> = 200, age 25.7, duration 13.7, 50% male	PAID (translated into Danish)	pre: control: 35.2 \pm 22.7, intervention: 36.4 \pm 21. Mean differences reported for intervention group only. Total: -8.7 ($p < .001$), men: - 2.6 (ns), women: - 15.3 ($p < .001$)	n/a

	Non-Intervention Studies						
Author, Year, Study Design (Country)	Study Purpose and Design	Participant Characteristics: mean age, mean diabetes duration / mean age at diagnosis, % male	DD Measure	DD Score (mean +/- standard deviation)	Associations with Other Outcomes	Limitations	
Downie G, 2019, cross- sectional, two time points 1 week apart (Australia)	Understand self- care intention and diabetes self- management behavior and DD	Time 1 $n = 287$, age 26.8, age at diagnosis 12.7, 17.8% male. Time 2 n = 167, age 27.1, age at diagnosis 13.7, 16.8% male	PAID	Time 1: 36.5 ± 17.3 ; Time 2: 34.57 ± 18.9 . PAID ≥ 40 : 49.1%	Increased DD associated with less frequent blood glucose monitoring (p < .01)		
Garvey K, 2017, cross- sectional (USA)	Compare transition experience of two groups: participants with Pediatric provider or with Adult provider	<i>n</i> = 602, age 22, age at diagnosis 9, 49% male	PAID	Pediatric provider: 27 ± 20 ; Adult provider: 31 ± 21 .	In Adult provider group, feeling prepared for transition was associated with lower DD ($p = .02$)		

Lasaite L, 2016 cross- sectional (Lithuania)	Compare adolescents to emerging adults and assess DD and other psychosocial variables	Adolescents: $n =$ 255 range 14- ≤ 18 , 48.2% male. Emerging adults: $n =$ 283 range 18-25, 48% male. Adolescent male median age 16.5, female median age 17. Emerging adult male median age 22, female median age 23	PAID (translated into Lithuanian)	Only reported stratified by gender and age. Medians, no SDs reported. Median adolescent: male 11.25, female 20. Median emerging adults: male 18.75, female: 25 (male $p = .002$, female $p = .016$). PAID $\geq 40 : 22.8\%$ of total, 17.2% adolescents, 27.9% emerging adults	DD associated with duration of diabetes $(p < .05)$.	Not longitudinal, compared two different groups
Quinn S, 2016, cross- sectional (USA)	Assessment of utility of psychosocial screening during transition, comparing chart review and screening using known measures	n = 43, age 18, diabetes duration 10, 47% male	DDS	No mean or median scores reported. 2/42 DD in chart review & DD on DDS, 1/42 no DD in chart review, but DD on DDS, 6/42 DD in chart review, but no DD on DDS	Six participants identified through chart review as having DD did not screen positive on the DDS	Authors hypothesize that DD not found on survey because it resolved in the interim.

Stahl-Pehe A,	Assessment of
2019, cross-	DD in young
sectional and	adults with
longitudinal	early-onset
(Germany)	diabetes (age 0-

Sample 1a: n = 208, PAID sessment of age 20.8, diabetes duration 17.4, 37.5% male. Sample 1b: n = 303, 4) in 2 cohorts age 22.4, diabetes duration 19.4, at 3 time points 41.6% male. Sample 2: n = 73, age 18.8, diabetes duration 14.9, 39.7% male

Cross sectional: Sample 1a: $19.1 \pm$ 16.1, PAID \ge 40: Higher DD was 13.9%. Sample associated with A1C $1bL\ 20.4\pm 16.1,$ (*p* < .001), female PAID \geq 40: gender (p < .001), 12.2%. Sample 2: low satisfaction with 22.6 ± 17.4 , PAID treatment (p < .001) ≥ 40: 16.4% and depression (p < p).001). Lower DD was associated with higher SES (p =.002) and better selfreported health status (*p* < .001). Longitudinal: Higher distress at baseline had higher A1C at follow-up when covariates controlled (p = .005)n/a

Tanenbaum	Describe	Total $n = 1503$,	DDS
M, 2017,	diabetes device	stratified by age,	
cross-	(pumps,	group ages 18-25: <i>n</i>	
sectional	continuous	= 515, no	
(USA)	glucose	demographics	
	monitors) use	reported by strata	

 2.21 ± 0.86 , compared to all other age strata (p <.001)

Vallis M, 2018, cross- sectional (trans- national)	Compare emerging adults 18-30 to adults over 30	Total $n = 1060$, Emerging adults: $n = 308$, age 24.97, diabetes duration 7.94, 48.7% male	PAID-5 (re- coded scores to 0- 100)	Emerging adult sample: 44.14 ± 24.73 , Adult sample: 38.86 ± 24.67 ($p = .001$) PAID-5 cutoff (>40 for re-coded scores): Emerging adult sample: 60.1% Adult sample: 50.8% ($p = .004$)	Stratified into early (18-24) & late emerging adults: Late phase had greater distress ($p =$.017), specifically on DDS: greater fear of living with diabetes, feelings of depression, worry over the future, feeling overwhelmed and trouble coping with complications
D 1. 1 A	· D.1 / C 1				with complications

^aProblem Areas in Diabetes Scale ^bDiabetes Distress Scale

Qualitative studies exploring diabetes distress (DD) in emerging adults

Author, Year,	Participant	Purpose	Themes
Study Design	Characteristics:		
(Country)	mean age or		
	range, mean		
	diabetes duration,		
	% male		
Abdoli S, 2017,	n = 9, age range	To gain a comprehensive	Main theme is "struggle towards adulthood" which
qualitative	18-30, 33% male,	understanding of emerging	included: transition to adult provider, issues with
descriptive semi-	all living in	adults with T1D living in	insurance and paying for supplies, social stigma because
structured	Appalachia	Appalachia	assumptions about T2DM, worries about complications,
interviews (USA)			fear of hypoglycemia, using technology, social
G 1 G	10 01		connections, feelings of hope
Calamaro C,	n = 12, age 21,	I o explore the healthcare	I hree themes: 1) lack of health information specific to
2018, qualitative	42% male, all	experiences of emerging	young adults, 2) emotional turbulence with forward
an alastronia	newly diagnosed	adults diagnosed with TTD	ninking, 3) needs of young adults (communication,
all electronic	botween age 17	Just prior to or during conege	pitysicai, psychosociai)
closed and open	Detween age 17-		
ended questions	23		
(USA)			
Carlsund A. 2019	n = 12, age 23	To describe emerging adults'	Used the word distress once. Two main themes and five
qualitative	diabetes duration	experiences of living with	subcategories: 1) handling the situation a) managing daily
descriptive semi-	14. 33% male	T1D	life. b) the emotional roller coaster. 2) dealing with
structured	, <i></i> , <i></i> , <i></i>		different opinions a) general attitudes and concerns, b)

DIABETES DISTRESS IN EMERGING ADULTHOOD

interviews (Sweden)			own views and apprehensions, c) ignorance and lack of motivation
Clausi L. 2017, phenomenological semi-structured interviews (Canada)	<i>n</i> = 7, age 20, no males, 100% female	To understand the influence of T1D on young women's perceived sense of self	Three themes: 1) want to be more free (burden, it is always there), 2) it is a part of me (routine, trying to stay positive), 3) want to be normal (stereotypes, feeling different, frustrations)
Ersig A, 2019, qualitative descriptive exploration of open ended questions (USA)	n = 25 college students and $n =$ 14 parents, age range 18-24, 17.4% male,	To understand the experience of living with T1D in college for students and their parents	Four themes in college students: 1) life stage stress, 2) diabetes management worries, 3) long-term implications and complications, 4) the importance of college-based social network
Fredette J, 2016, phenomenological semi-structured interviews (USA)	n = 24, age range 18-24, 13% male, all college students	To understand how T1D affects quality of life in emerging adults attempting to fully live the college experience	Three generally positive themes: 1) planning ahead, 2) thinking positive, 3) seeking support
Jeong YM, 2018 qualitative descriptive focus groups (USA)	n = 14, age 26.5, diabetes duration 13.1, 36% male	To explore health–related stigma among emerging adults with T1D	Used the word distress 15 times. Five themes 1) desire to be seen as a person, not a disease, 2) wanting to be "normal," 3) feeling ashamed managing diabetes in public, 4) struggling to overcome anger and distress, 5) feeling distrusted by others to manage their condition
Markowitz B, 2019, qualitative descriptive semi- structured interviews (Canada)	n = 33, age 20.6, diabetes duration 12, 49% male	To address the question: how does T1D fit into an emerging adult's evolving life story?	Used the word distress 6 times. Three story types identified using narrative approach: 1) ingrained narrative portrayed active integration of diabetes, 2) intrusive narrative characterized by struggle for acceptance, 3) inconspicuous narrative contained willingness to ignore diabetes and management tasks.

Ramchandani N,	n = 21 (18 in)	To explore developmental,	Used the word distress 3 times. Four themes: 1) finding a
2019, qualitative	focus groups, 4 in	situations and organizational	balance between diabetes and life, 2) the desire to be in
descriptive focus	interviews), age	challenges experienced by a	control of diabetes, 3) the hidden burden of diabetes, 4)
groups and semi-	23.6, diabetes	diverse group of emerging	the desire to have a connection with their diabetes
structured	duration 14.7,	adults with T1D to develop a	provider
interviews (USA)	29% male	diabetes management program	
Sanders T, 2018,	n = 15, age range	To explore the attitudes of	Three themes about participating in the diabetes
grounded theory	16-24, diabetes	emerging adults with T1D in a	education program: 1) "we're in it together," 2) tacit
semi-structured	duration 9, 47%	structured education program	benefits, 3) transitions beyond structured education
interviews and	male, all	and the implications for care	program
focus groups	participants in	transitions from pediatric to	
(UK)	structured	adult care.	
	diabetes		
	education		
	program		
Saylor J, 2019,	<i>n</i> = 12, age 21,	To gain insight about college	Four themes: 1) diabetes affects all aspects of life and
qualitative	diabetes duration	life experiences for emerging	complicates college living, 2) the college environment
descriptive focus	1.91, 42% male,	adults diagnosed with T1D	affects diabetes management, 3) diabetes diagnosis
groups (USA)	all newly	just prior to or during college	facilitates growth and maturity, 4) strategies used for
	diagnosed with		diabetes management in college
	diabetes between		
	age 17-25		

References for Chapter 2

(See Cumulative References)

Chapter 3

Diabetes Distress in Emerging Adults:

Refining the Problem Areas in Diabetes—Emerging Adult Version using Rasch Analysis

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Abstract

The emotional burden of living with type 1 diabetes (T1D) is experienced differently in each life stage. Thus the measurement of diabetes distress (DD) warrants tailoring to particular developmental stages, specifically emerging adulthood (ages 18-30). The new measure entitled the Problem Areas in Diabetes- Emerging Adult version (PAID-EA) is intended to be a developmentally-embedded measure of DD for use in clinical and research settings. The goal of the present study was to use Rasch psychometric analysis to reduce and refine the PAID-EA. Emerging adults with T1D (n = 194) completed the 30-item online survey. Evaluation of response category functioning, measurement precision, redundancy, unidimensionality and targeting guided item reduction through iterative revisions. The reduced and refined PAID-EA consists of 25 items and shows promising utility for clinicians and researchers. Approximately 1.4 million Americans live with type 1 diabetes (T1D) and both the prevalence and incidence of T1D have been increasing in recent years (Center for Disease Control and Prevention, 2020; Dabelea et al., 2014; Mayer-Davis et al., 2017). T1D is the result of the auto-immune destruction of insulin producing pancreatic beta cells, which is believed to be a consequence of a combination of genetics, environmental factors and multiple stochastic variables (Jeffrey et al., 2010). Intensive T1D management requires many complex daily tasks including blood glucose monitoring, carbohydrate counting and insulin administration (American Diabetes Association, 2020). The Diabetes Control and Complications Trial (DCCT) and the follow-up Epidemiology of Diabetes Interventions and Complications (EDIC) demonstrated that adherence to these multiple diabetes management tasks is critical to achieve target glycemic control, as reflected in lower hemoglobin A1C (A1C) levels, and to reduce diabetes complications (Nathan et al., 2005; Nathan et al., 1993).

Recent evidence suggests that emerging adults (ages 18-30) with T1D constitute a specific group that experiences worse glycemic control, more frequent severe hypoglycemia and more frequent diabetic ketoacidosis (DKA) than any other age group (Foster et al., 2019; Helgeson et al., 2018; McCarthy & Grey, 2018; Pettus et al., 2019; Schwandt et al., 2017). Despite many therapeutic and technological advancements, emerging adults are still developing microvascular complications of diabetes, including retinopathy and kidney disease, at a young age (Bryden et al., 2003; James et al., 2014). Additionally, emerging adults identify substantial burdens associated with the rigors of unending self-care needs and psychological outcomes, including depression, anxiety and disordered eating, tend to worsen during this developmental stage (Baucom et al., 2018; Johnson et al., 2013; Rassart et al., 2015).

Emerging adulthood is a unique developmental stage from ages 18-30, when youths experience multiple transitions, in education, occupation, geography and socialization (Arnett, 2000, 2015). Emerging adults with T1D experience all of these changes within the context of living with T1D. They often become geographically distinct from their parents for the first time, become increasingly financially independent and more in control of their own health and healthcare (Peters et al., 2011). Additionally, friends and romantic partners become the most meaningful relationships in their lives instead of their family of origin (Ersig, 2019; Raymaekers et al., 2017). These multiple transitions and stressors can magnify and exacerbate the diabetes specific emotional burden of living with T1D.

Diabetes distress (DD) arises from these specific stressors of managing T1D coupled with the pervasive nature of self-care needs and the challenges of achieving target glycemic control. Such distress can manifest as negative emotions; these emotions include feeling overwhelmed, hopeless, frustrated, worried, angry and guilty related to managing T1D (Kalra et al., 2018). These feelings can be exacerbated by a lack of understanding and support from family, friends and healthcare providers (Hagger et al., 2016; Sturt, McCarthy, et al., 2015). DD is associated with higher A1C levels, impaired quality of life and less frequent self-management behaviors (Joensen et al., 2013; Lerman-Garber et al., 2003). Additionally, it is important to note that though many of the emotions of DD overlap with depressive symptomology, DD is distinct from depression and is not considered psychopathology (Fisher et al., 2014). It is believed that elevated levels of DD can negatively affect future health outcomes by hindering the ability to accomplish all the daily tasks of diabetes care, in that the emotional burden makes it difficult to convert diabetes self-care intentions into actions (Fisher, Hessler, Polonsky, Strycker, et al., 2018; Gonzalez et al., 2011). Therefore, given the risk of poor health outcomes seen in emerging adults compared to other developmental stages, it is critically important, both clinically and for research, to have a measure of DD specific to this developmental stage.

This study used the Rasch model, as it is a useful and well-suited approach to evaluate instruments of clinically meaningful diagnoses, such as DD in emerging adults. Clinicians often view diagnostic assessment as along a continuum, where patients with low DD will identify certain thoughts or behaviors and patients with high DD will identify different thoughts or behaviors; this parallels the Rasch model's concepts of person ability and item difficulty. In fact, clinicians often think of diagnostic questions as having a certain range and degree of difficulty. So, the Rasch model is a perfect fit for assessing a measure designed to identify a clinically important construct that is hierarchical in progression along the clinical continuum and can be defined by items that vary from easy to difficult to endorse. The Rasch model is an appropriate choice for the evaluation of DD as the construct is assumed to be unidimensional and each item on the measure is intended to contribute equally to the identification of DD (Rasch, 1960). The primary aim of this study was to use Rasch analysis to reduce and refine the PAID-EA for clinical and research utilization.

Methods

The Measure

The known and previously validated measures of DD including the original PAID (Polonsky et al., 1995), the Diabetes Distress Scale (DDS) (Polonsky et al., 2005), the PAID-Teen (Weissberg-Benchell & Antisdel-Lomaglio, 2011) and the PAID-Peds (J. Markowitz et al., 2015) were compared and pertinent items were modified to address the experience of emerging adults. The initial pool of questions (40 items) were then reviewed, edited and expanded upon by eight healthcare providers of diverse specialties at the Joslin Diabetes Center, creating a pool of 60 items. To clarify the meaning and relevance of these items, a sample of 13 emerging adults with T1D piloted this 60-item pool via an online survey during the April 2019 NextGen Leadership Summit hosted by the College Diabetes Network (CDN), which is a nationwide non-profit organization whose mission is to empower and improve the lives of college students living with T1D. This same sample of 13 CDN members also participated in an informal focus group where they were prompted to reflect on the emotional burden of living with T1D as an emerging adult and to provide direct insight into the questions on the survey. The PAID-EA was conceptually clarified, edited and reduced to 30 items.

All items on the PAID-EA have a unified stem using "I" statements that reflect the negative emotional burden and stressors of living with T1D as an emerging adult. The PAID-EA response options are a 5-point Likert-type scale (0 = Disagree, 1 = Somewhat disagree, 2 = Neutral, 3 = Somewhat agree, 4 = Agree). A total distress score is computed by summing the responses. Higher scores indicate the emerging adult is experiencing more DD.

Data

Participants were recruited via CDN's social media network in three waves until the target sample of 150 participants was surpassed. Inclusion criteria were ages 18-30 and a diagnosis of T1D. Survey study procedures received Institutional Review Board approval prior to data collection. Additionally, seven informal cognitive interviews (G. B. Willis, 2004) with emerging adults living with T1D were conducted during data analysis to inform the interpretation of the Rasch analysis results, in particular the variable map and the item fit statistics.

Statistical analyses were performed using SPSS v26 (IBMCorp., 2020) and WINSTEPS v4.4.6 (Linacre, 2020b). All surveys that had missing responses on more than 10 items in the

PAID-EA were deleted. Remaining missing data appeared to be at random and no respondent had more than 4 missing items. The 16 missing data points were replaced with the mode of the response option for that item instead of using the WINSTEPS expected value calculation, which could possibly obscure item misfit and impede the refinement of the measure.

Rasch Analyses

The Rasch model is a probabilistic model, where the assessment of the probability that a person will answer a certain way is important. As a person's level of DD increases (person ability), the probability of being more likely to agree to that item goes up. Additionally, as items become indicative of more severe DD (item difficulty), the probability of disagreeing with that item goes up. In the Rasch model, the person ability and the item difficulty allow for the prediction of expected responses.

The PAID-EA was designed to capture this continuum from low DD to high DD and this study explored how this new measure fits the Rasch model. It is important to note that DD is not a complication of T1D, instead it is a normal and common part of living with T1D. Thus, it is close to impossible that a person living with T1D would experience absolutely zero DD. So the continuum of DD proceeds from low to medium to high and it is only when DD becomes elevated that it has a negative impact on outcomes. A person with low DD will be irritated and frustrated by the daily management tasks of diabetes and will experience some diabetes-specific worry about health and the future. As an emerging adult, these frustrations and worries are experienced within this developmental stage, where more explicit thinking about the future is an important developmental task. A person with a moderate amount of DD will experience more negative emotions. This emotional burden will begin to feel overwhelming, especially as an emerging adult is becoming independent from their family of origin, both in diabetes

management as well as emotionally and geographically. An emerging adult with high DD feels alone and stigmatized; these feelings influence how they interact with others, specifically how they engage in the developmental tasks of risk-taking and seeking a life partner. In fact, in a person with high DD, the severe emotional burden of T1D transitions from primarily being internalized to now being an externalized burden as well. This externally-focused burden is embedded within the developmental stage of emerging adulthood, where experiences are viewed reflexively through others, identity continues to be relationally defined and relationships with others are a priority. Additionally, very high DD begins to affect the ability to complete the multiple daily management tasks of diabetes as the escalating emotional burden impedes the ability to turn strongly desired self-care intention into action. Therefore, analogous to climbing a ladder, progress from low to high DD is marked by an additive process from simple frustrations that are commonly experienced to more severe negative emotional burden that ultimately affects interactions with others and diabetes management.

The algebraic form of the Rasch rating scale model used in this analysis is:

$$\pi_{nix} = \frac{\sum_{j=0}^{x_{ni}} e^{[\beta_n - (\delta_i + \tau_j)]}}{\sum_{k=0}^{m} e^{\sum_{j=0}^{k} [\beta_n - (\delta_i + \tau_j)]}}$$

where π_{nix} is the probability of person *n* responding in category *x* to item *i* where δ_i is the item difficulty and τ_j is the category threshold and β is the person's level of DD (Andrich, 1978). The location estimates, often reported as logits, were transformed for reporting purposes to a raw score ranging from 0 to 120. Respondents that have high DD have positive logits and respondents with low DD have negative logits. Additionally, items that are more difficult to endorse have positive logits and items that are easier to endorse have negative logits.

Refinement Method

To refine the PAID-EA, the 30-item measure was first evaluated extensively to assess fit with the Rasch model, then an iterative approach of analysis, review, selection and re-analysis was performed, guided by the process described by Wright and Stone (1979) in the dichotomous form and Wright and Masters (1982) in the polytomous rating scale form. First, response category functioning was examined. Then items were considered for removal, first by evaluating item misfit then by assessment of redundancy using the variable map. The Rasch model statistics were reviewed in parallel with the findings from the cognitive interviews to ensure individual item comprehension and content validity.

Results

The sample consisted of 194 emerging adults with T1D; 84% were female and one participant identified as non-binary. Participant age ranged from 18 to 30 years. Most participants (78.9%) were currently students, mostly as undergraduates. Diabetes technology was used frequently by this sample: 82.5% had used a continuous glucose monitor (CGM) in the last 30 days, where, in fact, almost half of participants did not check blood glucose (BG) levels at all because of CGM use, and 77.8% of participants had used an insulin pump in the last 30 days. Mean self-reported A1C was 7.4%. See Table 1 for details.

Initial Assessment of the 30-item PAID-EA using the Rasch Model

The 30-item PAID-EA has a person separation index of 2.56 with a separation reliability of 0.87, which demonstrated that the full measure is sensitive enough to distinguish between people with high and low DD. These values meet the acceptable criteria of > 2 for person separation and > 0.8 for reliability (Linacre, 2020a; Wright & Stone, 1999). Additionally, the item separation index was 6.2 with a separation reliability of 0.97 that confirmed the item continuum had a wide variance in difficulty and a large enough sample size to assess model fit.

These values meet the acceptable criteria of > 3 for item separation and > 0.9 for reliability (Linacre, 2020a; Wright & Stone, 1999). Additionally, the variable map of the full 30-item measure displayed how the variable of DD progresses along a continuum for both items and people (See Figure 1a). The variable map and the separation and reliability estimates showed that there is good spread across both people and items, in that the item difficulties cover a wide range of the continuum of DD and the participants' ability captured the full range of human potential within the construct of DD. Despite these positive findings, there appeared to be an opportunity for reduction and refinement of the PAID-EA.

Refining the PAID-EA

Response category functioning. The five category characteristics curves showed a good spread for the *Disagree* and *Agree* categories but the mid-level responses were not clearly distinguishable from one another. To refine the measure, collapsing the response options was initially undertaken: *Disagree* and *Somewhat Disagree* were combined, as well as *Agree* and *Somewhat Agree* to form 3 response options of *Disagree, Neutral* and *Agree*. This collapsing improved the separation of the response thresholds but it had detrimental effects on the overall results, where person separation dropped to 2.15 and the item separation dropped to 5.26. Additionally, the loss of score variability reduced the Cronbach's alpha from .904 to .875. Though this alpha is acceptable, the goal of the study was to reduce the number of items and along with the collapsing of the categories it was expected that alpha would reduce even further. Hence, the 5 response options were retained in order to maximize person and item spread along the continuum.

Misfit driven item removal. Twenty six of the 30 items on the PAID-EA had acceptable Infit and Outfit values (0.5 to 1.5 mean square unstandardized (MNSQ) and Outfit < 2.0 standardized cube-root transformation of the mean squares (ZSTD)), indicating possible measurement utility (Linacre, 2020a; Smith, Schumacker, & Bush, 1998; Wright & Masters, 1982). See Table 2 for details. Infit is based on squared residuals with each observation weighted by the model variance. Outfit is based on squared residuals too, but is more sensitive to unexpected responses on items that are expected to be very hard or very easy for a particular respondent. In this analysis, the unstandardized mean squares for both Infit and Outfit as well as the standardized statistics for Outfit were evaluated simultaneously to investigate any source of unexpected response variation that might aid in revising and reducing the PAID-EA.

Two items had excessive unstandardized Infit and Outfit misfit. Item P20 used the term "check a blood sugar," which was unclear to emerging adults in the cognitive interviews that wore CGM and thus did not check fingersticks, so it was deleted. The misfit for item (P25) was driven by two extremely misfitting respondents with surprising responses on only this one item; furthermore, this item was noted to be very relevant and valid in cognitive interviews, so item P25 was retained. Additionally, one item (P1) had excessive unstandardized Outfit misfit as well as disagreement among the emerging adults about whether they felt guilty or some other emotion, so this item was deleted. One additional item (P16) had a high standardized statistic and after re-analysis of the fit statistics with P20 and P1 deleted, this item also had excessive unstandardized Outfit misfit. This item also provoked conflicting thought processes identified in the cognitive interviews; so this item was deleted.

Redundancy driven item removal. The variable map was assessed to ensure a maximum range of content coverage as well as to remove any redundant items (See Figure 1a). On the right side of the variable map, items that are difficult to endorse are at the top and items that are easier to endorse are at the bottom. On the left side of the variable map, persons who scored high on the PAID-EA are at the top of the map and those who scored low are at the bottom. It is important to be able to locate both items and persons along this continuum so that you can "see" in between them because items and persons must be separated along this line for precise measurement of the construct (Wright & Stone, 1999). However, the 30-item full measure variable map had a rather large cluster of items in the middle that did not appear to discern much change in DD. Many of the items in this cluster had similar logit estimates or were so close in terms of their standard errors (SE) that the items could not be easily differentiated (See Table 2 for values). These items were considered for removal following the iterative process described by Wright and Stone (1979). In addition, many of these items were conceptually similar. In fact, in the cognitive interviews, emerging adults often described similar themes for these items and commented how certain questions reminded them of other questions in the interview.

Three items (P26, P28, P29) captured similar feelings of limitations when living with T1D and had very similar estimates and overlapping *SE*s, so only item P28 was retained and P26 and P29 were deleted. Two items (P6, P17) addressed complementary feelings of stigma and also had very close logit values and *SE*s, so item P6 was retained and P17 was deleted. Two items (P2, P3) captured related feelings of being overwhelmed by the work of T1D and had similar logit values and *SE*'s, so item P2 was retained and P3 was deleted. Finally, two items (P5, P12) described very similar feelings of burden to explain diabetes and feel understood by others, yet

the logit values and *SE*s were not as close as the above items. It is important to note that the middle cluster of items on the variable map had a very small difference between logits and often had overlapping *SE*s. These two items appeared in the middle cluster upon visual inspection of the variable map despite having further apart estimates and *SE*s. In an effort to continue to reduce conceptual redundancy, item P5 was retained and P12 was deleted.

Evaluation of the reduced PAID-EA. Upon deletion of these 8 items, (P1, P16, P20 due to misfit and P3, P12, P17, P26, P29 due to redundancy), the data were re-run and the variable map was re-assessed to confirm the conceptual continuum was maintained (See Figure 1b). The variable map clarified the a priori construct of DD and each rung of the conceptual ladder is noted in the box on the right in Figure 1b. Easier items are general frustrations and typical worries about life with T1D and indicate low levels of DD. However, this emotional burden is additive and builds to feeling overwhelmed by life with T1D as an emerging adult. When this DD becomes very high, the burden is reflected by others, in that this emotional work has an impact on emerging adults sense of self as perceived by others and on interactions with friends and romantic partners. Of note, there remains respondents with high DD that do not have matching hard items indicating that the measure may require additional items.

To further evaluate these revisions, item misfit was reassessed and all items were between 0.5 and 1.5 for either Infit or Outfit MNSQ and no items were above 2 for Outfit ZSTD. Additionally, this reduced measure had a person separation of 2.34 with a reliability of 0.85 and an item separation of 6.98 with a reliability of 0.98, both of which met the acceptable criteria as noted above. The Cronbach's alpha remained acceptable at 0.879 with the reduced number of items. Multiple strategies were utilized to assess unidimensionality of the reduced 22-item PAID-EA: a factor analyses using Principal Axis Factoring (PAF) of the raw data to provide additional context for the evaluation of a Principal Components Analysis (PCA) of the Rasch residuals and a parallel analysis of simulated data (Ludlow, 1985). For the raw data, the Kaiser-Meyer-Olkin (KMO) value was 0.863, a measure of sampling adequacy, which is in contrast to the KMO of the residuals which was .037. This demonstrates that the Rasch model accounted for a majority of the variability and there was not sufficient residual variation remaining to be factored.

Additionally, the ratio of the first to second eigenvalue from the PAF of the raw data was just under 4, while the ratio for the residual analysis was 1.2. Parallel analysis of simulated residual data produced a similar eigenvalue ratio of 1.02. Additionally, the PAF of the raw data showed that the first factor accounted for 29.3% of the variance, which exceeds the recommended 20% (Kaiser, 1970). Importantly, visual inspection of the unrotated plot of the first three components revealed a picture of items loading highly on the first factor and much lower on the remaining two factors. This plot is in comparison to the unrotated plot of the residuals, which showed a circular pattern, indicating a random relationship among items (Ludlow, 1985). These results, taken together, support the unidimensionality of the measure.

Interpretation of the refined PAID-EA. The Rasch analysis results support the conceptual continuum of DD, thus it can be useful to interpret scores on the PAID-EA for both clinical and research utility. On the reduced 22-item PAID-EA, scores can range from 0 to 88 and it can be useful to transform these raw scores into an average item response (Lysaght, O'Leary, & Ludlow, 2017). These average scores can inform not only how much DD a

respondent may feel but can also demonstrate where this respondent resides on the conceptual continuum (see horizontal lines on Figure 1b). A respondent with an average score of 1-1.9 experiences a low level of DD and feels frustrated by daily life with T1D. However, a respondent with an average score of 2-2.9 experiences increasing DD as evidenced by worries about their own health and future. Then, a respondent with an average score of \geq 3 experiences a high level of DD, feels overwhelmed by the emotional burden of T1D and this influences their interactions with others. These average scores can provide insight into the level of DD a respondent is experiencing and shows potential as a clinical diagnostic or cut point to identify those respondents with high DD.

Discussion

This refinement of the PAID-EA demonstrates that this developmentally-embedded measure of DD fits the Rasch model and confirms the clinical continuum distinguishing between low and high DD. This refined PAID-EA will fill the gap for a developmentally-based measure of DD in emerging adults.

Researchers and clinicians have long recognized the effect of developmental context on the experience of living with T1D and thus developed measures that capture those varied emotional experiences. Yet, the developmental context of emerging adulthood presents unique challenges, burdens and emotional work when managing T1D (Balfe et al., 2013). Of note, Quinn et al. (2016) completed retrospective chart reviews of emerging adults transitioning to adult diabetes care and compared elevated DD documented as a problem by the provider to DD identified by screening with the one of the known and previously validated measures of DD, the Diabetes Distress Scale (DDS). Providers documented DD in 8 of the 42 participants. Yet, the Thus, 75% of the patients with provider identified DD were not captured through the DDS screening. The authors attributed these results to a time lapse between the chart review and the DDS screening; they concluded that DD must have resolved in these participants by starting therapy or medication. Importantly, the authors did not recognize this finding as a possible limitation of the DDS measure in this population. Nonetheless, Quinn et al.'s (2016) results contribute to growing evidence that the known measures of DD may not be sensitive enough to DD within the developmental context of emerging adulthood and thus a new measure is needed.

Additionally, as diabetes technology and treatment modalities innovate, there is a need to address the terminology used in measures. In this analysis, it was clear that using the words "check a blood sugar" in item P20 was unclear to emerging adults who wore CGMs and do not check fingersticks. Simply one item lacking clarity can influence the results of the measure and potentially affect the testing of associations with other variables. In the known and previously validated measures of DD, it is important to also consider the clarity of language. The DDS uses the terms "testing a blood sugar" which is now perceived as a judgmental and pejorative term as it implies the possibility of failing, thus it is avoided. The PAID-Teen uses multiple references to "blood sugar checks," which was the exact issue identified in this analysis of the PAID-EA in a sample with high CGM use. The PAID-Peds uses "sugar levels" and though this may appear to apply to both fingersticks and CGM values, it may be a term that is unfamiliar to youth, so it may also be unclear. It is rather apparent from this revision and refinement of the PAID-EA that language is critical and must be inclusive, comprehensive and flexible.

Furthermore, measures must also be sensitive to cultural shifts. Of note, item P20 appeared to misfit statistically, however the cognitive interviews made it abundantly clear that

the cost of diabetes was a major concern for emerging adults. Though this particular statistical misfit was highly influenced by two respondents, the conversation about the cost of managing diabetes, especially the cost of insulin, is a hot social and political topic. Additionally, in 2010, emerging adults in the United States quickly became the test subjects for the Affordable Care Act's extension of parental insurance coverage up until age 26 (Collins & Nicholson, 2010). This conversation about the financial cost of living with T1D continues to evolve and will likely remain a worry, and thus a contributor to DD, for emerging adults for years to come. However, none of the known and previously validated measures of DD address this concern. This analysis was able to clarify the relevance and consequence of capturing this emotional burden in emerging adults.

This Rasch analysis resulted in refinement of the PAID-EA and demonstrated that the reduced measure has measurement precision and unidimensionality. Though Rasch analysis is often not used in clinical research arenas, it is a very appropriate and valuable analytic approach, especially when assessing a construct that exists on a continuum where certain thoughts or behaviors can indicate low levels of DD and other specific thoughts or behaviors can indicate high levels of DD. Rasch analysis is a powerful model that parallels a clinician's approach to diagnostic evaluation and provides valuable insight into the assessment of the emotional burden of living with T1D as an emerging adult. Thus, this study used an innovative approach to revise the PAID-EA to capture the experience of DD in emerging adults.

Despite the attention to rigor, this study does have some limitations. This study used a convenience sample of emerging adults recruited through CDN's social media accounts. This sampling technique captured mostly female college students, thus creating a young, gendered and highly educated sample, including a majority using advanced diabetes technologies (i.e.
insulin pumps and CGMs) with close to target glycemic control based on the reported A1C. It is possible that a sample of emerging adults with less well controlled diabetes may have yielded different findings. Future studies should focus on sampling a more diverse group of young adults. Additionally, since this was an online survey, it was impossible to calculate response rate and thus it cannot be assessed if respondents are different than those who did not respond. Also, as an online survey, all demographic and clinical variables were self-report with its inherent limitations.

Future Research

In an effort to improve the targeting of the measure (i.e. a closer alignment of the person and item locations on the continuum), additional questions were developed and revised in consultation with experts in the field and during additional cognitive interviews with emerging adults, including those representing a wider range of glycemic control. The purpose of these additional questions was to improve the targeting by including harder items that matched those people with higher DD. As noted above, harder to endorse items on the revised variable map (Figure 1b) represented burden reflected through others that appeared to be starting to affect selfcare actions. However, there are few items on the reduced measure that capture how the emotional burden affects the ability to complete the multiple daily management tasks of diabetes. So, the following items will be included for future revision and enhancement:

I am too tired of having diabetes to take care of it. I have other things in my life that keep me from managing my diabetes. I don't want to know my blood sugar when it is high.

The first item listed above is a duplicate of an item from the PAID Peds. This item reflects how the emotional burden (feeling tired of diabetes) affects self-care. The second item

intends to capture a similar concept, but addresses the difficulty of managing diabetes with conflicting priorities, which is often a challenge for emerging adults as they become more independent with diabetes and other life tasks. The third item is a revision of the deleted item P20, which contained an important concept, but was highly misfitting and appeared to lack clarity for emerging adults that wore CGMs and did not check fingersticks. This further revised and refined PAID-EA would consist of 25 items (22 items remaining from the Rasch analysis and the 3 above items) and requires additional psychometric evaluation.

Table 1.

Participant characteristics (N = 194)

	Mean \pm SD or % (Range)
Age (years)	21.2 ± 2.8 (18-30)
Sex (% female)	84%
Age at diagnosis (years)	11.4 ± 5.5 (2-26)
Currently a student	78.9%
First year	19.1%
Second year	17.5%
Third year	14.9%
Fourth year	15.5%
Later years / Grad School	11.9%
Used CGM in last 30 days	82.5%
Never check BG because of CGM	47.4%
Used pump in last 30 days	77.8%
Self-reported A1C (%)	$7.4 \pm 1.2 \ (5.2-13.4)$

Figure 1a. Variable map for 30-item PAID-EA

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   1
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                .### |
                         P8:romantic partner
              ######
                         P15: avoid when others around P7: alcohol
               .####
            #######
                         P14:feel alone
            .####### M|S
                         P17:worry something wrong P20:less likely to check when high P6:judged by others
                .###
            .#######
                         P10:sex P24:priority when changes
               .####
                         P21:living alone
               .##### | P11:get in the way P30:trying hardest P5:tired of explaining
                 ### | P13:must be perfect P2:mental energy
    0
               ###### S+M P19:overwhelmed by myself
                  .# | P16:blame high or low P3:burned out
                 .##
                         P12:don't understand P26:carry supplies P28:cannot take risks P29:plan
                      #
                      P1:off track
                  .#
                      P27:Low BG
                   #
                      .# |S P18:failure high A1C P23:complications
                   # T|
                         P9:having kids
                   #
                         P25:cost P4:ignorant comments
                   .
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    1
                         P22:interruptions
                      +
    2
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EACH "#" IS 2: EACH "." IS 1
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Note. Item deleted in revision of PAID-EA

Running Head: DIABETES DISTRESS IN EMERGING ADULTHOOD



Figure 1b. Variable map for reduced 22-item PAID-EA

_______<less>|<freq> EACH "#" IS 2: EACH "." IS 1 Table 2.

Rasch item fit statistics for the 30-item PAID-EA.

Item	Item	Infit	Infit	Outfit	Outfit	Item	Model
Number		(MNSQ)	(ZSTD)	(MNSQ)	(ZSTD)	(logit)	Standard
P1	I feel guilty when I get "off track" with my diabetes management.	1.19	1.61	1.54**	3.40**	-0.23	0.07
P2	I feel that diabetes is taking up too much of my mental energy every day.	0.63	-4.23	0.67	-3.16	0.04	0.06
P3	I feel "burned out" by the constant work of managing diabetes.	0.74	-2.67	.79	-1.70	-0.09	0.07
P4	I feel annoved when people say something ignorant about having diabetes.	1.26	1.58	1.19	1.06	-0.83	0.10
P5	I am tired of having to explain diabetes to others.	1.09	0.97	1.10	0.88	0.20	0.06
P6	I feel judged by others because I have diabetes.	0.92	-1.01	0.90	-1.04	0.45	0.06
P7	I worry about being able to socialize because of how alcohol affects my blood sugar.	1.14	1.63	1.15	1.44	0.78	0.06
P8	I worry that a new romantic partner will see my diabetes devices or supplies.	1.24	2.63	1.18	1.69	0.83	0.06
P9	I worry about having kids in the future because of my diabetes.	1.36	2.35	1.20	1.20	-0.59	0.09
P10	I worry that my blood sugar will go low or high during sex.	1.06	0.69	1.05	0.51	0.30	0.06
P11	I worry that diabetes will get in the way of what I want to do with my life.	0.91	-1.00	0.91	-0.78	0.14	0.06
P12	I feel frustrated when my friends and family don't understand my diabetes.	0.91	-0.79	0.88	-0.88	-0.18	0.07
P13	I feel that I must be perfect in my diabetes management.	1.04	0.47	1.04	0.41	0.10	0.06
P14	I feel alone with diabetes.	0.78	-2.81	0.79	-2.25	0.62	0.06
P15	I avoid doing diabetes management tasks when other people are around.	1.00	0.01	1.01	0.13	0.77	0.06
P16	I blame myself when my blood sugar is high or low.	1.22	2.01	1.32*	2.36**	-0.08	0.07
P17	I worry people will think there is something wrong with me because I have	0.85	-1.78	0.81	-1.93	0.39	0.06
D10	diabetes.	0.95	1 15	0.97	0.94	0.54	0.09
P18	I feel like a failure when I have a high ATC.	0.85	-1.15	0.87	-0.84	-0.54	0.08
P19 D20	I feel overwheimed about having to do diabetes all by myself.	0.01	-4.4/	0.62	-3.64	0.02	0.06
P20 D21	I am less likely to check a blood sugar when I know it is nigh.	1.03***	0.23	1.84**	0.72^{++}	0.39	0.06
P21	I worry about hving alone because I have diabetes.	1.14	1.4/	1.19	1.72	0.21	0.06
P22	I feel frustrated about interruptions from diabetes (during sleep, work, school).	1.11	0.07	1.11	0.01	-0.99	0.11
P23	I worry about diabetes complications.	1.01	0.10	0.95	-0.25	-0.50	0.08
P24	l don't know how to make diabetes a priority when I have a lot of changes in my life.	0.93	-0.//	0.98	-0.15	0.30	0.06
P25	I worry about the cost of diabetes.	1.62**	3.36	1.51**	2.54**	-0.82	0.10
P26	I am frustrated that I have to carry my diabetes supplies everywhere.	1.16	1.40	1.22	1.57	-0.20	0.07
P27	I worry about having a low blood sugar.	1.10	0.85	1.28	1.80	-0.37	0.08
P28	I feel like I cannot take as many risks as my friends.	1.03	0.30	0.96	-0.29	-0.13	0.07
P29	I feel angry that I have to plan so much when I go anywhere.	0.72	-2.67	0.69	-2.49	-0.20	0.07
P30	I feel like I am trying my hardest to take care of diabetes, but it never works.	0.77	-2.70	0.75	-2.38	.017	0.06

** <0.5 or >1.5 threshold for MNSQ or >2 for Outfit ZSTD. * >1.5 threshold for MNSQ after 2 items were deleted.

References for Chapter 3

(See Cumulative References)

Chapter 4

Assessing Diabetes Distress in Emerging Adults: Development and Validation of the Problem Areas in Diabetes—Emerging Adult Version

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This manuscript represents a significant portion of the Dissertation work and represents portions of the methods and results sections of the traditional dissertation. Ms. Wentzell is the primary author on this manuscript and Dr. Vessey is the senior author on this manuscript. This manuscript is ready to submit at the time of dissertation defense.

Abstract

Background: Emerging adults (ages 18-30) with type 1 diabetes (T1D) experience worse glycemic control and psychological outcomes compared with other groups. The emotional burden of the unending self-care needs of diabetes management appears to be related to these poor health outcomes. However, there is no validated measure of this emotional burden specifically in the developmental context of emerging adulthood. **Purpose:** The primary aim of this study was to examine the psychometric properties of a new measure of diabetes distress (DD) for use with emerging adults with T1D. Methods: In this cross-sectional study, emerging adults with T1D completed an online survey, including measures of DD, depressive symptomology and the newly developed measure, the Problem Areas in Diabetes—Emerging Adult version (PAID-EA). Participants also answered demographic and clinical outcomes questions. Internal consistency, reliability, construct validity and the underlying factor structure of the PAID-EA were assessed. **Results:** Participants (N = 287, 78% female) had a mean age of 24 ± 3.6 years; 43.4% were full-time students; 78% wore an insulin pump; 89.9% used a continuous glucose monitor (CGM) in the last 30 days; mean self-reported A1C was $7.1 \pm 1.2\%$. The PAID-EA demonstrated good internal consistency and reliability (Cronbach's $\alpha = .89$), was comprised of one component accounting for 28.9% of the observed variance and demonstrated construct validity as it was significantly correlated with known measures of similar constructs, as well as with A1C levels (rho = .20, p = .001). Conclusions: The PAID-EA holds promise as a reliable and valid measure of DD in emerging adults.

Keywords: Type 1 diabetes, Emerging adults, Diabetes distress, Measurement

Acknowledgements:

The authors would like to acknowledge the College Diabetes Network, social media influencers in the diabetes online community and the Diabetes Education and Camping Association for their assistance in recruitment. Emerging adults (ages 18-30) with type 1 diabetes (T1D) navigate the many normative milestones of this developmental stage within the day-to-day context of diabetes management (Monaghan et al., 2015; Peters et al., 2011). During this life stage, emerging adults face many transitions and high levels of instability that can exacerbate the diabetes-specific stressors of life with T1D (Arnett, 2015; Balfe et al., 2013). Recent evidence suggests that emerging adults with T1D constitute a specific group that experiences worse glycemic control as well as more frequent episodes of severe hypoglycemia and diabetic ketoacidosis (DKA) than any other age group (Foster et al., 2019; Helgeson et al., 2018; McCarthy & Grey, 2018; Pettus et al., 2019; Schwandt et al., 2017).

Diabetes distress (DD) is the set of negative emotional or affective experiences that result from living with the unrelenting self-care demands of diabetes management (Skinner et al., 2019). Elevated DD is associated with higher hemoglobin A1C (A1C) levels, impaired quality of life and less frequent self-management behaviors (Joensen et al., 2013; Lerman-Garber et al., 2003). It is believed that the effect of DD on glycemic control is mediated by self-care behaviors where the negative emotional burden of T1D reduces self-efficacy and motivation to complete the repetitive, multiple daily management tasks of diabetes required to reach target glycemic control.

It is important to note that DD is experienced within the developmental context of one's life stage. During this developmental stage, emerging adults usually become geographically distinct from their parents for the first time, become increasingly financially independent and assume more control of their own health and healthcare (Peters et al., 2011). Additionally, friends and romantic partners become the most meaningful relationships in their lives instead of their family of origin (Ersig, 2019; Raymaekers et al., 2017). These multiple transitions and stressors can magnify and exacerbate the diabetes-specific emotional burden of living with T1D.

Yet, despite the acknowledgment of the effect of life stage on the experience of DD for children (Evans et al., 2019; J. Markowitz et al., 2015), adolescents (Weissberg-Benchell & Antisdel-Lomaglio, 2011), parents of youth with T1D (Evans et al., 2019; J. Markowitz et al., 2012; Shapiro et al., 2018) and adults (Polonsky et al., 1995; Polonsky et al., 2005), there is no measure of DD specific to the developmental context of emerging adulthood. Thus, current measures may fail to capture the developmental hurdles, the many layers of transition and the high levels of uncertainty that characterize living with T1D during this time period (Wentzell, Vessey, & Laffel, 2020). Because of this underestimation, it may be difficult to determine significant associations between DD and A1C levels, diabetes management adherence and other outcomes.

Therefore, the purpose of this study was to evaluate the psychometric properties of a newly developed measure of DD for use with emerging adults living with T1D, the Problem Areas in Diabetes–Emerging Adult Version (PAID-EA). Specifically, internal consistency, reliability, construct validity and the underlying factor structure of the PAID-EA were assessed. Additionally, associations with demographic and clinical variables as well as between group differences in PAID-EA scores were explored.

Methods

Design

To address study objectives, a cross-sectional, online survey methodology was employed. The minimum sample size was determined *a priori* using a subject-to-item ratio of 10, bringing the required sample size to at least 250 (Nunnally, 1978).

Recruitment

Three online recruitment approaches were undertaken to engage emerging adults with T1D. First, the College Diabetes Network (CDN), which is a 501c3 non-profit company whose mission is to empower and improve the lives of students and young adults living with T1D, posted information about study recruitment on their social media accounts (Facebook, Instagram and Twitter). These posts were shared in multiple online forums, such as reposting on personal profiles, sharing in closed groups and by individuals tagging friends. Secondly, multiple emerging adult social media influencers in the diabetes online community were recruited to share a story or post on Instagram about the importance of research or their own experience with the emotional work of T1D. Then, the approved recruitment language appeared in the comments of the post. These influencers received \$20 for their recruitment efforts. As recruitment continued, it became apparent that young men appeared to be less engaged with diabetes content on social media than young women, so young men specifically were targeted in a recruitment effort through the Diabetes Education and Camping Association listserv for directors of diabetes camps, encouraging them to share with staff and alumni recruitment language asking young men to participate. Recruitment lasted for 3 months.

Procedures

By clicking on the link in one of the above recruitment methods, participants were directed to the Qualtrics survey platform (Qualtrics, 2005). Inclusion criteria were that participants must be over 18 years old, have T1D, be able to read and write English and provide consent to participate. The online consent page presented risks, benefits, the purpose of the study, confidentiality and contact information. All participants had the opportunity to enter a raffle for one of five \$100 Amazon gift cards. All phases of this project were approved by the Institutional Review Board. Additionally, social media recruitment was designed and conducted in accordance with available ethical recommendations (Bender, Cyr, Arbuckle, & Ferris, 2017; Franzke, Bechmann, Zimmer, Ess, & The Association of Internet Researchers, 2020; Gelinas et al., 2017).

Measurement

The online survey included demographic and clinical questions: age, self-identified gender, self-identified racial/ethnic background, student status and year in school, age at diagnosis of T1D, self-reported most recent A1C, use of a continuous glucose monitor (CGM) in the last 30 days, use of an insulin pump in the last 30 days and frequency of fingerstick blood glucose checks. To approximate socioeconomic status, median household income from United States Census data was captured by the participant provided home zip code (U.S. Census Bureau, 2019). Additionally, one question assessed the severity of the impact of the COVID-19 pandemic on the participant's life and one question asked if the pandemic had affected their mood, as recent evidence suggests that the pandemic has psychosocial consequences in people living with diabetes (Joensen et al., 2020).

The first measure included in the study was the original Problem Areas in Diabetes (PAID) measure, which includes 20-items about of the emotional burden of living with diabetes (Polonsky et al., 1995). Over consecutive evaluations, the PAID has shown excellent reliability and responsiveness (Welch et al., 1997; Welch et al., 2003). Additionally, the PAID been used extensively across the world, has been translated into 10 languages and has demonstrated high cross-cultural reliability (Schmitt et al., 2016). The PAID includes items such as "Feeling scared when you think about living with diabetes," "Worrying about low blood glucose reactions" and "Worrying about the future and the possibility of serious complications." The PAID is scored

using a 5-point scale on how much each diabetes issue is currently a problem (0 = Not aproblem, 1 = Minor problem, 2 = Moderate problem, 3 = Somewhat serious problem, 4 = Seriousproblem). The scores for each item are summed, then multiplied by 1.25 to generate a total score of 0 - 100. The PAID's initial validation created a cut-off of ≥ 40 (Snoek et al., 2015; Welch et al., 1997; Welch et al., 2003), and more recently, Hermanns et al. used receiver operating characteristic curve analysis to determine a cut-off of ≥ 33 for clinically significant distress (2006). For the current study, the presence of a high level of DD was defined as PAID score \ge 40. Moderate, possibly clinically significant DD was defined as scores between 33 and 39.

Next in the survey was the newly developed and refined PAID-EA. The initial pool of questions (40 items) was developed by the first author based upon her clinical experience caring for emerging adults with T1D, a thorough review of the literature as well as by comparing and contrasting items on the PAID (Polonsky et al., 1995), the Diabetes Distress Scale (DDS) (Polonsky et al., 2005), the PAID-Teen (Weissberg-Benchell & Antisdel-Lomaglio, 2011) and the PAID-Peds (J. Markowitz et al., 2015). Pertinent items were then modified to address the experience of emerging adults. These questions were then reviewed, edited and expanded upon by 8 healthcare providers of diverse backgrounds at the Joslin Diabetes Center creating a pool of 60 items. To clarify the meaning and relevance of items, this 60-item pool was piloted with a sample of 13 members of CDN during the NextGen Leadership Summit in April 2019. This same sample of 13 CDN members also participated in an informal focus group where they were prompted to reflect on the emotional burden of living with T1D as an emerging adult and to provide direct insight into the questions on the survey. This process allowed for the reduction from 60 items to 30 items.

This 30-item measure was then reduced and refined using the Rasch model, which is a psychometric model that examines the continuum between a person's level of DD (person ability) and items indicative of more severe DD (item difficulty), to create a 22-item measure with 3 questions added to improve item targeting (Wentzell, Vessey, Laffel, & Ludlow, 2020). The refined 25-item PAID-EA reflects the emotional burden of living with T1D specific to the developmental stage of emerging adulthood. For example: "I don't know how to make diabetes a priority when I have a lot of changes in my life," "I feel alone with diabetes," "I worry that a new romantic partner will see my diabetes devices or supplies," "I worry about being able to socialize because of how alcohol affects my blood sugar," "I feel overwhelmed about having to do diabetes all by myself," and "I feel like I am trying my hardest to take care of diabetes, but it never works." The PAID-EA is scored using a 5-point Likert-type scale (0 = Disagree, 1 =Somewhat disagree, 2 = Neutral, 3 = Somewhat agree, 4 = Agree). A total distress score is computed by summing the responses. Total scores can range from 0 to 100; higher scores indicate the emerging adult is experiencing more DD. The PAID-EA has a Flesch-Kincaid reading grade level of 5.4.

The final measure was the Center for Epidemiologic Studies Depression Scale (CES-D), one of the most frequently used self-report assessments of depressive symptoms (Radloff, 1977), that is used extensively in diabetes research (Dijk et al., 2018). The CES-D is a 20-item measure consisting of 16 negatively worded items (e.g. "I felt sad," "I felt I could not shake the blues even with help from my family or friends," "I thought my life had been a failure") and four positively worded items ("I felt happy," "I enjoyed life," "I felt that I was just as good as other people," "I felt hopeful about the future"). The CES-D is scored using a 4-point scale on the frequency of experiencing these feelings during the past week (0 = Never or rarely (less than 1

day), 1 = 1-2 days, 2 = 3-4 days, 3 = Most or all of the time (5-7 days)). Positive items are reverse coded and the responses were summed, creating scores that can range from 0 to 60, so that higher scores indicate greater frequency of depressive symptoms (Radloff, 1977). There have been a few different CES-D cut-off scores identified as clinically meaningful in different population studies (Gemma, Carlos, Gabriela, & Jordi, 2016). For this study, clinically significant depressive symptoms were defined as a score ≥ 16 , a threshold that has been used in adults and youth with diabetes (Lawrence et al., 2006; Lloyd, Pambianco, & Orchard, 2010; Peyrot & Rubin, 1997).

At the end of the online survey, several open-ended questions were included. One question asked which emotion, worry or feeling related to living with diabetes asked about in the earlier items was the most important or significant to the participant. Another question asked if there was anything that was missed in the prior items about the emotional burden of living with diabetes. The entire series of online surveys took approximately 10-15 minutes to complete.

Analyses

Statistical analyses were performed using SPSS v26 (IBMCorp., 2020). Categorical data are presented as frequencies while data for continuous variables are summarized using appropriate measures of central tendency and dispersion (e.g. mean and standard deviation, median and range). Prior to analysis, extensive data cleaning was conducted to remove surveys containing no data and remove responses from participants who did not meet the inclusion criteria. Additionally, a bot was detected during data collection and per Pozzar et al.'s (2020) recommendation, fraudulent or suspicious data were identified in any survey that was completed in less than 3 minutes and contained no responses to the open-ended questions, resulting in the

deletion of 429 surveys. After this data cleaning, responses for any participant completing less than 80% of the PAID-EA were removed (n = 4) (final sample PAID-EA N = 287). In the remaining PAID-EA surveys, no item had more than 3 missing responses. Additionally, if the PAID or the CES-D was less than 80% complete, the responses for that measure were deleted and were not included in the analyses (final sample PAID: N = 286, CES-D: N = 282). Remaining missing data in all measures appeared to be random. Only a few data points were missing (PAID-EA: 18, PAID: 2, CES-D: 7), so missing data were replaced with the mode of the response option for that item as the data was categorical and to allow for comprehensive item analysis in this initial psychometric evaluation.

Item analysis was undertaken to assess item difficulty, discrimination, and corrected and uncorrected item-to-total correlations. Reliability analysis was conducted to assess internal consistency using Cronbach's alpha. To determine if the PAID-EA was appropriate for factoring, Bartlett's test of sphericity and Kaiser-Meyer-Olkin (KMO) test for sampling adequacy were assessed (Bartlett, 1954; Kaiser, 1970, 1974). To examine the internal structure of the data, the PAID-EA items was subjected to exploratory factor analysis using principal components analysis (PCA). Inclusion of components were assessed by examining the scree plot (Catell, 1966) as well as comparison with a parallel analysis (Horn, 1965).

Spearman correlations were used to determine the strength and direction of relationships with clinical variables, to assess criterion validity using the PAID as a gold standard and to evaluate convergent validity with the CES-D serving as an established measure of a similar construct. Additionally, two-tailed independent sample t-tests and one-way between groups analysis of variance (ANOVA) with Sheffe test for post-hoc pairwise comparisons were conducted to explore demographic differences in DD. A p value of <.05 indicated significance.

Responses to the open-ended questions were reviewed and organized by theme; these results were used to help inform the interpretation of the above statistics as well as for confirmation of content validity.

Results

Participant characteristics

The study sample consisted of 287 emerging adults with T1D, with a mean age of 24 years (range 18-30) (See Table 1). Seventy-eight percent identified as female and 3 participants (1%) identified their gender in another way. Though 93% identified as white, 10.1% identified with another race, either exclusively or in addition to white, and 10.8% identified as being of Hispanic origin. Many in the sample were students, with 43.4% as a full-time student and 7.3% as a part-time student. Additionally, reflective of the healthcare transitions that occur during this life stage, 46.7% had their own health insurance, whereas 51.9% remained on their parents' health insurance and 1.4% were uninsured. These emerging adults used a substantial amount of diabetes devices: 77.9% wore an insulin pump recently, 89.9% used a CGM recently and 58.9% reported they never check a fingerstick blood glucose because they wear a CGM. Given the relatively high diabetes device use in this sample, it is not unexpected that the sample had a mean A1C of $7.1 \pm 1.2\%$ (range 4.9% - 11.4%), near the American Diabetes Association's recommended target of <7% (American Diabetes Association, 2021). Finally, to begin to understand the impact of the COVID-19 pandemic, about two-thirds of participants reported that the pandemic had a moderate or severe impact on their life (65.5%) and that their mood was worse than it was previously (69.3%).

Reliability analyses

Cronbach's alpha for the PAID-EA measure was .89. Corrected item-total correlations (item discrimination) ranged from .280 to .656, all above the .2 minimum value for retention in the measure (Briggs & Cheek, 1986). There were 2 items between .2 and .3 (Item 21: I worry about the cost of diabetes: .280 and Item 9: I worry that my blood sugar will go low or high during sex: .248). It is important to note that upon examination of the inter-item correlation matrix, Item 21 had a very low correlation with other items (range .096 to .264) as this item had the highest mean score of 3.52, such that almost all participants agreed with this item. Therefore, the item was less correlated with the other range of emotional experiences of diabetes. Consideration was taken to explore how Item 9 (mean score 2.21, correlation with other items ranged from 0.14 to .294) functioned in the remaining analyses as it addressed the developmental stage specific task of intimacy while living with T1D. Importantly, the deletion of any item would not have raised the Cronbach's alpha above .89. Thus, all 25 items were retained.

As the PAID-EA item responses were continuous, item difficulties were described as the arithmetic mean for each item and ranged from 1.32 to 3.52 (with options from 0 to 4), suggesting that participants endorsed much of the emotional burden described in the items and experienced a high level of DD (See Table 2), despite their relatively reasonable glycemic control. Item difficulties appear to spread across the clinical continuum of DD identified in a prior Rasch analysis (Wentzell, Vessey, Laffel, et al., 2020). Easier to endorse items reflect common frustrations around the cost of diabetes (Item 21), irritation with diabetes interruptions (Item 18) and annoyance with ignorant comments about diabetes (Item 2). Harder to endorse items speak to the emotional burden in relation to others, such as diabetes and romantic partners (Item 7), socially drinking alcohol with diabetes (Item 6) and also the avoidance of doing diabetes tasks around others (Item 13).

Factor analyses

An exploratory approach (PCA) was employed to examine the dimensionality of the PAID-EA and to understand the number of components underlying the measure. The KMO test for sampling adequacy was 0.897 and the Bartlett's Test of Sphericity was significant, $\chi^2(300) = 2150.71$, p < .001, indicating an analyzable correlation matrix and appropriateness for factoring. A single component solution accounted for 28.9% of the variance (See Table 2). An inspection of the scree plot revealed a clear break after the first component (See Figure 1) and this was further supported by the results of parallel analysis, demonstrating only one component with an eigenvalue exceeding the criterion value for a randomly generated data matrix of the same size (25 variables for 287 participants). All items loaded strongly on the single factor and all items were above the minimum factor loading of .2 (range .272 to .713) (See Table 2).

Construct validity

Evidence supporting criterion-related validity was observed for the PAID-EA as scores were significantly correlated with scores on the PAID (rho = .76, p < .001). Additionally, evidence of convergent validity was observed for the PAID-EA as scores were significantly correlated with scores on the CES-D (rho = .61, p < .001). Scores on the PAID-EA were also significantly correlated with A1C (rho = .20, p = .001).

Emotional burden of T1D in emerging adults

This sample of emerging adults carried a substantial emotional burden of life with T1D. Using the clinically significant cut-offs for the PAID, 47.2% of participants met the criteria for high DD (PAID score \geq 40), with an another 11.9% meeting the criteria for moderate DD (PAID score 33-39). Additionally, this sample endorsed a considerable amount of depressive symptomology, where 60.6% met the criteria for clinically significant depressive symptoms (CES-D score ≥ 16). Though determining clinically significant cut-offs for the PAID-EA is beyond the scope of this paper, emerging adults reported mean PAID-EA score of 59.5 \pm 17.6 (range 9-94) and a median score of 61, both of which are substantially above a score of 50, indicating an average of "Neutral" responses on the entire measure. Importantly, no participant indicated "Disagree" for all items on the PAID-EA, thus demonstrating that all participants identified in some way with at least a few items on the PAID-EA.

Many items were particularly strongly endorsed by participants (see Table 2). The most common concern for participants was Item 21: "I worry about the cost of diabetes" with 71.1% of participants endorsing "Agree." The other items where greater than 50% of participants endorsed "Agree" are: Item 18: "I feel frustrated about interruptions from diabetes (during sleep, work, school)" at 57.5%, Item 2: "I feel annoyed when people say something ignorant about having diabetes" at 53% and Item 8: "I worry about having kids in the future because of my diabetes" at 52.3%. Only one item was strongly negatively endorsed, with 51.6% of participants responding "Disagree:" Item 7: "I worry that a new romantic partner will see my diabetes devices or supplies."

Demographic differences in DD

This sample included emerging adults who described their gender in a variety of ways; there was a significant difference in PAID-EA scores when comparing those who identified as female, male and another gender identity (F (2, 284) = 9.43, p < .001), where those who identified as female ($M = 61.4 \pm 16.1$) were significantly different from males ($M = 51.7 \pm 20.7$) and those participants who endorsed another gender identity ($M = 78.3 \pm 6.8$) were significantly different than males. However, significant differences in PAID-EA scores were not noted between those who endorsed another gender identity and female participants. Also, PAID-EA scores were significantly correlated with age (rho = -.12, p = .04) but not with age at diagnosis (rho = .11, p = .07). Furthermore, there was no significant difference in PAID-EA scores between those participants who identified as white or identified as another race (which included participants who identified as both white and another race, 10.1% of the sample) (t(285) = -.56, p = .58), as well as between emerging adults who identified as not being of Hispanic origin and those who did (t(285) = -.24, p = .81).

Interestingly, there was no significant difference in PAID-EA scores between those participants who had their own insurance, were on their parents' insurance or were uninsured (F(2, 284) = 2.83, p = .06). Additionally, when examining the median household income from the United States Census data that corresponded to the zip code that the participant identified as home, there was no significant difference in PAID-EA scores between income categories of <\$50,000, \$50,001-75,000, \$75,001-100,000 and >100,000 (F(3, 264) = .37, p = .78).

The participants who reported their lives were moderately or severely impacted by the COVID-19 pandemic (65.5% of the sample) had significantly higher mean PAID-EA scores ($M = 62.4 \pm 16.6$) compared with those who were less impacted ($M = 54.1 \pm 18.2$; t(285) = 3.9, p < .001). Additionally, those participants who reported their mood was worse during the pandemic (69.3% of the sample) had significantly higher mean PAID-EA scores ($M = 63.5 \pm 16.3$) compared with those participants reporting no change or an improvement in mood ($M = 50.4 \pm 17.1$; t(285) = 6.2, p < .001).

Content Validity

Open-ended questions provided an additional opportunity for insight into the content validity and functioning of the PAID-EA. Almost all participants (263, 91.6%) responded to at least one of the open-ended questions; 212 participants responded to the question about which

emotions related to living with diabetes were not included in the survey and over half of those responses (50.9%) indicated that nothing was missed in the survey. A review of the remaining responses identified many feelings or worries that were in fact included in the measure. Some participants identified feelings or worries that were intentionally avoided in the development of the items because there are other known, validated measures of the construct, such as disordered eating behaviors, fear of hypoglycemia and anxiety. Additionally, the open-ended question about the most important or significant feeling related to living with T1D supported the of content validity for several items that also appeared to be particularly meaningful during the psychometric validation process discussed here and in the prior Rasch analysis (Wentzell, Vessey, Laffel, et al., 2020). These items included the worry about cost of diabetes, the worry about the future (complications, having children) and how diabetes affects relationships with others (romantic partners, friends). Taken together, the open-ended responses provided evidence supporting the content validity of the PAID-EA from the stakeholders who live with these emotions every day.

Discussion

Emerging adults with T1D negotiate the many transitions and challenges of emerging adulthood within the context of life with T1D. In order to elucidate this experience, it is critical to be able to accurately measure the emotional burden of living with T1D within this developmental context. Findings from this study provide evidence supporting internal consistency, reliability and demonstrate the PAID-EA is composed of one main factor. Construct validity of the PAID-EA is supported by strong correlations with both the PAID and the CES-D, as well as a significant, yet weaker, correlation with participant-reported A1C. Additionally, the conceptual continuum of low to high DD identified in the prior Rasch analysis of the PAID-EA (Wentzell, Vessey, Laffel, et al., 2020) is also supported by the current findings, where easier to endorse items speak to the irritations and frustrations of life with T1D, progressing to feelings of burnout and isolation, then moving to burden that is reflected through relationships with others which may impact the ability to complete the daily tasks of diabetes. It is also important to note that the three items added to improve item targeting during the prior refinement of the measure appeared to function well and reflected more difficult items as intended.

These findings also demonstrate that this age group experiences a clinically significant amount of diabetes-specific emotional burden and depressive symptomology. Though further research is needed, these results contribute to potentially clarifying the reasons why this age group experiences worse diabetes-related outcomes. In fact, a recent international consensus statement encouraged the measurement of DD in intervention studies designed to improve outcomes in emerging adulthood for this exact reason (Byrne et al., 2017). Accordingly, as a result of this study, the PAID-EA demonstrates potential to capture the emotional burden within the developmental context and may be useful to help evaluate effectiveness of interventions in this age group.

The PAID-EA includes many developmental stage-specific experiences, and, to our knowledge, it is also the first measure to include an item addressing the financial burden of living with diabetes in a measure of DD. Our findings demonstrate that this worry is substantial for emerging adults living in the United States. Some psychometric approaches recommend eliminating items that are skewed low or high to reduce floor or ceiling effects and possibly improve internal consistency, however this approach may actually miss items that speak to very important experiences. Reponses to open-ended questions revealed a colossal worry about the cost of diabetes and emerging evidence suggests that this concern is substantial for emerging

adults specifically (Blanchette et al., 2019; Blanchette et al., 2020). Interestingly, these findings clarify that concern about cost may not be related to insurance coverage or financial resources, as seen by the non-significant difference in PAID-EA scores between those that have their own insurance, those on their parents' insurance and those uninsured, as well as by the non-significant difference among the median household income categories for the zip code identified as home. Therefore, this worry may be independent of access to insurance or financial resources in emerging adults. Further study is needed to clarify this finding, as insurance and the financial burden of diabetes is particularly complex.

This study also revealed significant gender identity-based differences in PAID-EA scores. Though this sample was largely female, others have noted that female emerging adults may experience more severe DD than males (Lasaite, Dobrovolskiene, et al., 2016; Stahl-Pehe et al., 2019) and this pattern has emerged in other populations as well (Forsander, Bogelund, Haas, & Samuelsson, 2017; Perrin, Davies, Robertson, Snoek, & Khunti, 2017; Tanenbaum et al., 2017). Importantly, this study described that emerging adults who gender identify in ways other than male or female may experience worse DD. Gender identity-based differences in DD will be important to clarify and consider when designing interventions to improve DD.

Though exploring intimacy and seeking a partner are major developmental milestones in emerging adulthood (Arnett, 2000; Erikson, 1963), these findings suggest that this experience may be highly specific to the individual, as indicated by the less consistent responses to the worry about blood glucose during sex as well as less concern about romantic partners seeing diabetes devices. This may be reflective of the wide age range of this sample, where some participants are in college while some have started their careers, and some are still seeking a partner while others are settled in a long term relationship. Recent research highlights how the type of relationship impacts the worry about diabetes during intimacy (Garza et al., 2020; Pinhas-Hamiel et al., 2017). In future research, it will be important to tease out these differences to further explain how T1D may influence intimacy during emerging adulthood with both new and long-term partners.

It is becoming clear that the COVID-19 pandemic has had a substantial impact on many young people. The results of this study suggest that emerging adults who describe a more consequential impact of the pandemic or experienced a worsening of their mood during this time also reported more DD. During this moment in history, young people have lived through the COVID-19 pandemic, Black Lives Matter protests and a tumultuous Presidential election. Though this study only captured the specific impact of the pandemic, this year has presented many unanticipated life-altering challenges for emerging adults, potentially more so than other age groups, and this experience may have altered their ability to cope with the negative emotions related to life with T1D. This impact will need to be explored for many years to come. However, these results begin to describe and demonstrate the consequences of this historical moment on emerging adults' emotional experience.

Despite attention to rigor, this study does have a few limitations. This study used a convenience sample of emerging adults recruited through social media and electronic communication. This sampling technique captured a sample of mostly white females with higher socioeconomic status, with a majority using advanced diabetes technologies and with close to target glycemic control based on reported A1C. Though the authors took an intentional approach to outreach (i.e. reaching out to more black, indigenous, of color and gender diverse social media influencers) and ultimately captured a sample with a moderate amount of diversity, until social media is more inclusive and equitable, this sampling issue will persist. Future studies should

focus on the recruitment of a more diverse sample, including emerging adults who gender identify in ways other than male or female. Lastly, as this was an online survey, it was impossible to calculate response rate and thus it cannot be assessed if respondents are different than those who did not respond. Also, as an online survey, all demographic and clinical variables were self-report with its inherent limitations.

These findings support the PAID-EA as a promising, reliable, valid and developmentallyembedded measure of DD in emerging adults. Though the PAID-EA must be subjected to further psychometric testing, including determining the ideal scoring strategy and clinically useful cutoff point scores, the PAID-EA has the potential to advance the science of measurement of the emotional burden of T1D for both clinical and research use. The PAID-EA could be used clinically to help identify emerging adults who need additional support, to potentially improve glycemic control, to reduce acute complications such as severe hypoglycemia and DKA and to prevent the development or exacerbation of psychological issues such as depression and anxiety. Additionally, the PAID-EA will be sensitive to the worries and frustrations that are specific to emerging adulthood, which will allow this measure to be able to test for associations and potentially begin to explain why emerging adults have worse outcomes than other age groups. By clarifying these associations, interventions can be designed to reduce DD and change the health trajectory of emerging adults living with T1D. Table 1.

Participant demographics (N = 287)

	Mean \pm SD or % (Range)
Age (years)	24 ± 3.6 (18-30)
Sex (% female)	78%
Identify another way	1%
Age at diagnosis (years)	$11.3 \pm 6.1 (1-26)$
Race (% white)	93%
Identify as another race (can include white)	10.1%
Hispanic origin	10.8%
Median household income for home zip-code	\$77,020 ± \$31,136
-	(\$19,628 - \$208, 212)
Currently a Full-time student	43.4%
Part-time student	7.3%
Have own health insurance	46.7%
On parents' health insurance	51.9%
Uninsured	1.4%
Used insulin pump in last 30 days	77.9%
Used continuous glucose monitor in last 30 days	89.9%
Never check fingerstick blood glucose	58.9%
because of continuous glucose monitor	
Self-reported A1C (%)	7.1 ± 1.2 (4.9-11.4)
COVID-19 impact on life (% moderate or severe)	65.5%
COVID-19 impact on mood (% worse than before)	69.3%

Table 2.

Item difficulties and component loadings for the PAID-EA (N = 287)

Number	Item content	Mean \pm SD	Component 1
1	Too much mental energy	2.5 ± 1.3	.694
2	Annoyed about ignorant comments	3.3 ± 0.9	.353
3	Tired of explaining	2.4 ± 1.3	.537
4	Other things in life get in the way	2.0 ± 1.3	.515
5	Judged by others	1.9 ± 1.4	.520
6	Alcohol and socializing	1.5 ± 1.5	.539
7	Romantic partner & diabetes	1.3 ± 1.5	.446
8	Kids in the future	3.1 ± 1.3	.516
9	Blood sugar during sex	2.2 ± 1.5	.272
10	Diabetes will get in the way of my life	2.3 ± 1.4	.649
11	Must be perfect	2.6 ± 1.3	.478
12	Feel alone	1.8 ± 1.5	.594
13	Avoid doing diabetes around others	1.5 ± 1.4	.530
14	Failure when high A1C	3.1 ± 1.1	.488
15	Overwhelmed all by myself	2.4 ± 1.4	.674
16	Living alone	2.2 ± 1.6	.475
17	Don't want to know when high	1.9 ± 1.6	.509
18	Interruptions	3.4 ± 0.9	.508
19	Complications	3.2 ± 1.1	.502
20	Lots of changes	3.2 ± 1.1	.664
21	Cost of diabetes	3.5 ± 0.9	.320
22	Low blood sugar	2.9 ± 1.2	.394
23	Too tired to take care	1.7 ± 1.5	.636
24	Cannot take risks like friends	2.8 ± 1.4	.627
25	Try hard but it never works	2.1 ± 1.4	.713

Figure 1. Scree plot of eigenvalues for the PAID-EA items, demonstrating the point of inflection at the second component supporting a single-component solution.



References for Chapter 4

(See Cumulative References)

Chapter 5

Cumulative Discussion

The overall question driving this program of research was: How do the challenges of emerging adulthood inform our understanding of DD? Emerging adults with T1D navigate the many normative milestones of this developmental stage within the day-to-day context of diabetes management. Therefore, the overall purpose of this program of research was to develop and validate a new measure of DD for use with emerging adults. To accomplish this purpose, three specific aims were proposed. Each aim was addressed in a different manuscript; the work and its explications progressed in a step-wise fashion to collectively form a single, cohesive body of work. Taken together, this research (1) demonstrated that DD is prevalent and severe, yet qualitative studies describe a complex and multifaceted emotional experience in emerging adults with T1D, (2) presented a new measure of DD, entitled the Problem Areas in Diabetes-Emerging Adult version (PAID-EA) that was reduced and refined using Rasch Analysis and (3) presented a psychometric validation grounded in classical test theory of the PAID-EA and explored associations with related constructs and demographic variables. This body of work identified a critical gap in the existing literature and filled that gap through the development and validation of a new measure for use with the emerging adult population. This final chapter of this dissertation summarizes the findings from each of the three manuscripts within the context of relevant literature, examines the overall strengths and limitations of this work, and discusses how this work advances the science theoretically, methodologically and clinically.

To provide the reader with a brief overview, the study aims and key findings are summarized in Table 1 below.

Table 1.

Specific aims and findings

understanding of diabetes distress (DD).				
Aim	Findings			
<u>Aim 1:</u> Describe how emerging adulthood impacts DD through an integrative review of both quantitative and qualitative studies	 In emerging adults, DD is highly prevalent, severe and worse than in other age groups. Qualitative studies revealed the emotional burden of T1D is more complex and developmental stage specific than may be captured in current measures. 			
<u>Aim 2:</u> Develop, reduce and refine a new developmentally appropriate measure of DD in emerging adults entitled the Problem Areas in Diabetes- Emerging Adult (PAID-EA).	 Item reduction was conducted through iterative revisions guided by evaluation of response category functioning, measurement precision, redundancy, unidimensionality and targeting. The PAID-EA was reduced to 22-items and 3 items were added to improve item targeting. The reduced and refined PAID-EA fits the specifications of the Rasch model. 			
<u>Aim 3:</u> Test and validate the PAID-EA using classical test theory and assess associations with related constructs.	 The PAID-EA demonstrated good internal consistency and reliability (Cronbach's α = .89). The PAID-EA was comprised of one component accounting for 28.9% of the observed variance. The PAID-EA demonstrated construct validity as it was significantly correlated with known measures of similar constructs as well as with A1C levels. Participants that identify as female or another gender identity and those that have been severely impacted by the COVID-19 pandemic have significantly higher PAID-EA scores. However, there was no significant difference in PAID-EA scores by race, ethnicity, type of insurance or median household income. 			

Overall Purpose: Explore how the challenges of emerging adulthood inform our

Cumulative Discussion

The emotional burden of living with T1D during emerging adulthood is substantial.

Recent evidence reveals that DD is highly prevalent in emerging adults, where rates range from

28% to over 60% (Downie et al., 2019; Lasaite, Ostrauskas, et al., 2016; Vallis et al., 2018). DD also appears to be particularly severe during this developmental stage, with many reports revealing a sample with a mean DD score above the clinical cut-off point for elevated DD (Bakhach et al., 2019; Downie et al., 2019; Spaic et al., 2019; Tanenbaum et al., 2017; Vallis et al., 2018; Zoffmann et al., 2015). Emerging adults also appear to have significantly more DD than other age groups across the lifespan (Lasaite, Ostrauskas, et al., 2016; Tanenbaum et al., 2017; Vallis et al., 2018). Similar to other age groups, elevated DD in emerging adults is also correlated with both poor adherence to diabetes management tasks and worse glycemic control (Downie et al., 2019; Stahl-Pehe et al., 2019).

Though this picture is cause for alarm, it remains important to examine these reports within the context of measurement theory, as all of contemporary empiricism is undergirded by the assumption that we can accurately measure the human response to health and illness. In order to understand our world and develop new knowledge, we must be able to accurately and validly measure it. There is recent evidence that inappropriate or inadequate assessment may occur when using known, validated measures of DD developed for adults in an emerging adult population. As discussed previously, Quinn et al.'s (2016) retrospective chart review study compared elevated DD documented as a problem by the provider to DD identified by screening with the Diabetes Distress Scale (DDS). The DDS screening was positive for clinically significant distress for only two of the eight participants that had elevated DD on chart review. Thus, 75% of the patients with provider identified DD were not captured through the DDS screening. These findings contribute to growing evidence that the known measures of DD may not be sensitive enough to DD during emerging adulthood.
These findings are particularly impactful if one considers the developmental stage theory of emerging adulthood (Arnett, 2000, 2015) that clarifies the unique social and emotional challenges of this stage. This developmental context profoundly influences the emotional experience of living with T1D. In fact, all 5 facets of the stage theory of emerging adulthood impact the experience of DD, as seen in the conceptual map that was presented in Chapter 1 (See Figure 1).



Figure 1. Conceptual map of how developmental stage theory affects diabetes distress

So it follows that a measure of DD must include this context, just as other measures have recognized the developmental stage specific experience of youth (Antisdel, 2000; Evans et al., 2019; J. Markowitz et al., 2015) and their parents (J. Markowitz et al., 2012); adolescents (Weissberg-Benchell & Antisdel-Lomaglio, 2011) and their parents (Evans et al., 2019); and adults (Polonsky et al., 1995; Polonsky et al., 2005). Therefore, to accurately measure DD in emerging adults, emotions and experiences specific to this developmental stage need to be

included. The design and development of the Problem Areas in Diabetes—Emerging Adult version (PAID-EA) took the entirety of this developmental context into consideration for inclusion in the measure, as well as the common emotional experiences that exist throughout the lifespan (See Appendix B for the PAID-EA in full).

Items in the PAID-EA were designed to reflect the major concerns identified within the qualitative work discussed in Chapter 2, to follow the conceptual continuum from low to high DD as described using Rasch analysis in Chapter 3, and then this continuum was confirmed and reliability and validity was demonstrated using classical test theory approaches in Chapter 4. The discussion that follows will integrate and synthesize these results by following the progression from easier to endorse items that correspond to low DD to harder to endorse items that correspond to high DD. This is the Rasch conceptual continuum, similar to a ladder, where the emotional burden is additive and contributes to escalating DD. As a person's level of DD increases (person ability), the probability of being more likely to agree to that particular item goes up. Additionally, as items become indicative of more severe DD (item difficulty), the probability of disagreeing with that item goes up. The PAID-EA was intentionally designed to capture this continuum from low DD to high DD. Furthermore, the classical test theory validation results support the conceptual continuum identified in the Rasch analysis, so Table 2 depicts the parallels between these two analyses to organize and unify this body of work.

To further clarify, Table 2 displays the classical test theory item difficulty results, as evidenced by the item means and standard deviations. Items have been reordered from easy to endorse (high item mean at the bottom of the table) to hard to endorse (low item mean at the top of the table), directly next to the conceptual continuum results from the Rasch analysis. Of note, the variable map is not displayed here as the items were renumbered in the refined 25-item

PAID-EA.

Table 2.

Item difficulty from classical test theory analysis compared to Rasch analysis continuum

Classical test theory item difficulties			Rasch continuum
Number	Item content	Mean ± SD	
7	Romantic partner & diabetes	1.3 ± 1.5	Escalating effect on
13	Avoid doing diabetes around others	1.5 ± 1.4	self-care
6	Alcohol and socializing	1.5 ± 1.5	
23*	Too tired to take care	1.7 ± 1.5	
12	Feel alone	1.8 ± 1.5	
5	Judged by others	1.9 ± 1.4	Other reflected
17*	Don't want to know when high	1.9 ± 1.6	burden
4*	Other things in life get in the way	2.0 ± 1.3	
25	Try hard but it never works	2.1 ± 1.4	
9	Blood sugar during sex	2.2 ± 1.5	
16	Living alone	2.2 ± 1.6	
10	Diabetes will get in the way of my life	2.3 ± 1.4	Overwhelmed
3	Tired of explaining	2.4 ± 1.3	
15	Overwhelmed all by myself	2.4 ± 1.4	
1	Too much mental energy	2.5 ± 1.3	
11	Must be perfect	2.6 ± 1.3	
24	Cannot take risks like friends	2.8 ± 1.4	XX /
22	Low blood sugar	2.9 ± 1.2	Worry
14	Failure when high A1C	3.1 ± 1.1	
8	Kids in the future	3.1 ± 1.3	
19	Complications	3.2 ± 1.1	
20	Lots of changes	3.2 ± 1.1	
2	Annoyed about ignorant comments	3.3 ± 0.9	Frustration
18	Interruptions	3.4 ± 0.9	
21	Cost of diabetes	3.5 ± 0.9	

As seen in the above table, the classical test theory validation results correspond nearly exactly with the Rasch results. Additionally, the 3 items added to improve item targeting in the Rasch conceptual continuum (Item 4, 17 and 23, identified by "*" above) are in fact more difficult to endorse items, as intended. It is important to explore this body of work and address specific items within the context of the literature on the emotional burden with T1D in emerging adults. Of note, this discussion will focus on items that are representative of the themes contained within the conceptual continuum and this exploration will not undertake every item in the measure.

One of the most easily endorsed item in both analyses addresses the worry about the cost of diabetes (Item 21: I worry about the cost of diabetes). Recent evidence clarifies that contemporary American emerging adults carry an overwhelming worry about the financial burden of living with T1D (Abdoli et al., 2017; Blanchette et al., 2019; Blanchette et al., 2020; Ersig, 2019). Emerging adults are navigating life with diabetes while trying to become financially independent and, for the first time, are utilizing the healthcare system entirely on their own. This experience, combined with the reality of other costs of living, can be particularly daunting during this developmental stage. Notably, the PAID-EA is the first measure of DD that includes an item about the financial burden of life with diabetes. Furthermore, the thematic review of the open-ended questions confirmed that this worry was substantial as many participants identified the cost of diabetes as the biggest worry in all of the questions on the survey. This body of work also begins to clarify that this concern about cost may not be related to insurance coverage or financial resources, as seen by the non-significant difference in PAID-EA scores by type of insurance (carried their own, were on their parents' or uninsured) or by estimated median household income. Therefore, in emerging adults, this worry may in fact be

independent of access to insurance or financial resources and warrants further exploration as an easily endorsed item. It will be important to further clarify this worry across the heavily disparate insurance coverage among both private and public plans.

Additionally, items that addressed general frustrations with diabetes were relatively easy to endorse (Item 2: I feel annoyed when people say something ignorant about having diabetes). Though minor irritations about obtuse comments are likely common across the age span, within the developmental stage of emerging adulthood, these frustrations may be especially challenging as the work of diabetes is often experienced through the lens of others during this stage (Abdoli et al., 2017; Calamaro et al., 2018; Carlsund & Soderberg, 2019; Clausi & Schneider, 2017; Jeong et al., 2018; B. Markowitz et al., 2019; Ramchandani et al., 2019; Sanders et al., 2018; Saylor et al., 2019). Though other measures of DD include items that address uncomfortable social situations, the PAID-EA is more direct in asking about the stigma that emerging adults encounter in social contexts and the frustration with false perceptions about diabetes. The burden of stigma (the experience of negative feelings, including rejection or blame) reflects the emotional work that is related to other's perceptions. This frustration is particularly relevant to emerging adults, as identity continues to be relational and connections to others are a priority during this developmental stage

Emerging adulthood is also characterized by worry resulting from more explicit thinking about future health as the invincibility of adolescence fades (Item 19: I worry about diabetes complications) and this worry can become more substantial as young people begin to think about starting a family in the future (Item 8: I worry about having kids in the future because of my diabetes) (Abdoli et al., 2017; Calamaro et al., 2018; Ersig, 2019; Fredette et al., 2016). Although worries about the future can occur at any age, the transition to emerging adulthood from adolescence marks the loss of invulnerability and a more attendant awareness of mortality. Within this developmental context, increasing DD is experienced as increasing worry, mirroring the increasing difficulty of these items.

Emerging adults can feel overwhelmed with diabetes during the many transitions of this life stage, such as moving, starting a career and especially as they take on more responsibility for their own health (Item 15: I feel overwhelmed about having to do diabetes all by myself) (Balfe et al., 2013; Jeong et al., 2018; B. Markowitz et al., 2019). Emerging adults can experience the management of diabetes as being overwhelming, tiresome and as work that "just adds a really extra thick layer to everything" (p. 76) (Saylor et al., 2019). The burden and associated feelings of burnout are unique to the emerging adults' developmental stage, where their experiences occur within the midst of a substantial amount of transition and uncertainty, leading emerging adults to feel overwhelmed as a result of embracing this new independence and self-reliance.

Higher levels of DD can have repercussions on emerging adults' relationships with others. Relationships, with friends and romantic partners, are a significant developmental milestone during this life stage (Arnett, 2000; Erikson, 1963). Worries around T1D within normative risk-taking experimentation can impair socialization with peers (Item 6: I worry about being able to socialize because of how alcohol affects my blood sugar) (Carlsund & Soderberg, 2019; Ramchandani et al., 2019; Saylor et al., 2019). As emerging adults explore intimacy with new partners and develop long-term partnerships, diabetes can affect these relationships (Item 9: I worry that my blood sugar will go low or high during sex) (Carlsund & Soderberg, 2019; Ramchandani et al., 2019; Saylor et al., 2019). These items are considered hard to endorse as they correspond to high levels of DD. Specifically, these items address how the escalating emotional burden of T1D affects the cultivation of both social and intimate relationships during this developmental stage.

As DD becomes more severe, the negative emotional burden of T1D reduces motivation and self-efficacy to complete the multiple daily management tasks of diabetes (Item 13: I avoid doing diabetes management tasks when other people are around) (Clausi & Schneider, 2017; Jeong et al., 2018; B. Markowitz et al., 2019). These items are among the hardest to endorse as they reflect how the emotional burden associated with T1D gets in the way of completing diabetes tasks. It is hypothesized that this barrier is the reason for the association between elevated DD and poor adherence to diabetes management tasks and worse glycemic control (Skinner et al., 2019). In sum, the most difficult to endorse items that correspond to the highest levels of DD and address DD's escalating effect on emerging adult's ability to complete the tasks of self-care.

It remains important to note that all of the aforementioned worries, fears and emotions that reside within this developmental stage are not included in any of the current, validated measures. Notably, the PAID-EA also captures emotions and experiences that are likely common across the life span, such as perfectionism, feeling like a failure and fear of hypoglycemia. However, the evidence shows that even when there are common experiences across all life stages, there are also very specific experiences and burdens that occur only during this unique developmental stage (Balfe et al., 2013). In order to measure the full experience of DD during this time, we have to capture these developmental stage specific issues as well, in the same way other measures capture the unique experiences specific to youths, adolescents and adults.

Finally, these studies provide strong evidence supporting the PAID-EA as a psychometrically sound measure. Through Rasch analysis, the PAID-EA has been shown to be a

115

developmentally-embedded measure of DD that fits the Rasch model, confirms the conceptual continuum distinguishing between low and high DD and has measurement precision and unidimensionality. The result was a 25-item measure. Using methods grounded in classical test theory, the PAID-EA was confirmed to be psychometrically sound, with excellent internal consistency, reliability and a structure comprised of one main factor. Additionally, evidence supporting construct validity was contributed by significant correlations with both the original PAID and the Center for Epidemiologic Study-Depression survey (CES-D), as well as with higher A1C levels.

Strengths and Limitations

This body of work demonstrates that the PAID-EA has great potential as a reliable, valid measure of DD in emerging adults. The PAID-EA has been subjected to review and validation using two very different rigorous approaches, both Rasch analysis and classical test theory based analysis. It is rare that a new measure is subjected to both approaches during refinement and validation; in fact, no other measure of DD has been subjected to psychometric validation grounded in both item response theory (Rasch analysis) and classical test theory. Thus, the superior rigor of this dual approach supports the precision, consistency and validity of the PAID-EA.

The PAID-EA is the first measure of the developmentally specific experience of DD in emerging adults. Though researchers have long recognized the developmental context of youth, adolescents and adult's experience of DD, emerging adulthood has not been seen as different or unique (Wentzell, Vessey, & Laffel, 2020). The PAID-EA was developed following a thorough review of the literature as well as in consultation with expert clinicians, and most importantly, from insight directly from emerging adults living with T1D. The PAID-EA addresses a number of very specific experiences of emerging adulthood, including navigating relationships and transitions. The PAID-EA is the first measure of DD that addresses the worry associated with the financial strain of diabetes, which is particularly pertinent for emerging adults that are just beginning to gain their financial footing.

Also, as identified in the Rasch analysis, the language and word choice used in measures, as well as diabetes in general, can be influential (Dickinson, 2018; Dickinson et al., 2017). As diabetes technology and treatment modalities evolve and improve, there is a particular need to address the terminology used in measures. In the Rasch analysis described in Chapter 3, it was clear that an item that included the phrase "check a blood sugar" was unclear to emerging adults that wore CGMs and did not check fingersticks. Notably, even one item lacking clarity can adversely affect the measure and potentially alter the ability to test associations with other variables. Language is critical and must be both inclusive and flexible. Therefore, the refined PAID-EA simply refers to knowing the value of a blood sugar, expanding the application to fingersticks, CGM data and likely any future technology to maintain the relevance of the language in the PAID-EA for many years to come.

Despite attention to rigor, this body of work has a few limitations. The primary limitation of this research is the use of social media as a recruitment tool for both phases of this body of work, which has the potential to contribute to a restricted sample. As a result, the sample is limited to participants who have social media accounts and engage with content specific to diabetes online. Even though social media is often a source of support and camaraderie for people living with T1D (Litchman et al., 2020; Oser et al., 2020; Tenderich, Tenderich, Barton, & Richards, 2019; Warshaw et al., 2019) and 90% of emerging adults use at least one social media site (Pew Research Center, 2019), not all people engage with diabetes or health-related

content on social media (Fergie, Hunt, & Hilton, 2016). Additionally, social media platforms sometimes have unequal gender distributions in their users (Pew Research Center, 2019), an issue that became evident through a majority of female participants in the two data collections discussed here. Even though recruitment through social media may have contributed to this inequity, others have also reported difficulty recruiting young men for studies on the emotional burden of T1D in emerging adults (Balfe et al., 2013; Cabassa, Hansen, Palinkas, & Ell, 2008). Of note, the original validation of the PAID was conducted with only female participants (Polonsky et al., 1995).

Additionally, as this research utilized social media influencers to recruit participants, it is critical to point out that influencers may not be representative of a given population because they tend to be heteronormative and relatively able-bodied. To mitigate this sampling issue, an intentional approach to outreach was undertaken (i.e. reaching out to more influencers that identified as black, indigenous, of color and gender diverse), however until the influencer space is more diverse, inclusive and equitable, this issue will remain. Finally, since this research used an anonymous, online survey, it was impossible to calculate response rate and thus it cannot be assessed if respondents are different than those who did not respond. Also, as an online survey, all demographic and clinical variables were self-report with its inherent limitations.

The current cultural moment in history has the potential to dramatically impact all clinical studies conducted during this time period. During recruitment for this body of research, emerging adults experienced not only the COVID-19 pandemic, but also Black Lives Matter protests and a tumultuous Presidential election. Emerging adults may be particularly susceptible to the emotional impact of these experiences (Bort & Aleah, 2020; Fry, Passel, & Cohn, 2020; Sherman, 2020). In an attempt to explore this effect during the most recent recruitment wave,

two quantitative questions and two open-ended questions asked about the impact of the COVID-19 pandemic on the participant's life, mood and life with T1D specifically. However, this cultural moment is likely much more complex than simply life during the pandemic and its effects on emerging adults may not be able to be completely described for years to come. Finally, even though these historical moments may influence each participant in different ways, all participants lived through these events as a common and shared experience.

Advancing the Science

Theory

It is important to reflect on the foundations of the nursing discipline to clarify and illustrate how describing the emotional burden of T1D advances nursing knowledge. It should be recalled that contemporary empiricism is undergirded by the assumption that we can accurately measure the human response to health and illness (Weiss, 1995). In order to understand our world and develop new knowledge, we must be able to measure it. Moreover, it is the drive towards improving practice that makes measurement a valuable and worthy research pursuit (Donaldson & Crowley, 1978). Describing an emotional phenomenon is the first step. Only after that, associations with other clinical observations can be explored and allow for clarification of the phenomenon. Then, once the phenomenon is fully described, a clinical intervention can be developed to impact future health outcomes. The foundation of this entire process is the need to measure accurately, without bias and with minimal error (Dillman, Smyth, & Christian, 2014), as well as with the confidence that the construct being measured is in fact the construct that was intended to be measured (Creswell & Creswell, 2018).

Yet, to influence health outcomes, it is important to recognize that the world of nursing practice is complex and empirics alone may be inadequate at times (Chinn & Kramer, 2008).

Nursing's unique and multifaceted perspective remains essential despite a cultural push towards only empirical knowing being valuable (Fawcett, Watson, Neuman, & Hinton, 2001). In fact, nursing knowledge that uses all the ways of knowing to describe our world and impact practice is what defines our nursing identity as a discipline (Chinn & Kramer, 2008) with the unifying goal of facilitating humanization (G. D. Willis, Grace, & Roy, 2008) especially in populations that are understudied or disadvantaged (Grace & Perry, 2013; Grace & Willis, 2012). Emerging adults have long been ignored as a distinct developmental stage. So, by creating a measure to describe emerging adults' experience of the emotional burden of living with T1D, knowledge is developed that will continue to advance nursing in a way that is in line with its unique knowledge and disciplinary identity.

Furthermore, this body of work contributes to advancing the stage theory of emerging adulthood, as it demonstrates that the experience of DD during this stage is different and filled with unique experiences of diabetes that are specific to this stage alone. It is important to note that emerging adults have traditionally been excluded from stage theory. Effectively, the meaningful years of emerging adulthood have been lost in between the division of pediatric and adult healthcare and research (Tanner, 2006). For many years, emerging adults with T1D have been combined with older adults in research studies, potentially obscuring the distinct challenges, developmentally, socially and emotionally, experienced by this age group when managing diabetes (Weissberg-Benchell et al., 2007). Therefore, recognizing the differences in this developmental stage and designing a measure to capture this experience will contribute to the advancement of the stage theory of emerging adulthood.

Methodology

Though Rasch analysis is often not used in clinical research arenas, it is a very appropriate and valuable analytic approach, especially when assessing a construct that exists on a continuum where certain thoughts or behaviors can indicate low levels of DD and other specific thoughts or behaviors can indicate high levels of DD. Rasch analysis is an item response theory model that parallels a clinician's diagnostic approach and provides valuable insight into the assessment of the emotional burden of living with T1D as an emerging adult. By utilizing Rasch analysis, this study used an innovative approach to revise the PAID-EA to capture the experience of DD in emerging adults. Notably, Rasch analysis is often viewed as supplemental to classical test theory approaches. Instead, in this body of work, Rasch analysis was the first step in reduction and refinement. By focusing on individual respondents (person ability) and specific items (item difficulty) the Rasch model allowed for a very targeted examination of the PAID-EA through an iterative process to consider items for removal or refinement. This body of work contributes to the Rasch measurement literature by continuing to expand the use of this analytic approach into the clinical sphere.

Furthermore, this body of research used innovative methods to recruit a hard-to-reach population. Emerging adults with T1D have long been recognized as a group that is hard to recruit and retain for clinical research studies (Clarke et al., 2018; Galea & Tracy, 2007; Hanna et al., 2014). In particular, young men have been identified by other researchers as an extra challenging population to recruit for research on emotions (Choi et al., 2017; Ellis et al., 2012; Ellis et al., 2013). Though this body of work encountered many of these challenges when recruiting using social media, this research contributes to the awareness of how social media platforms can open up global avenues across age groups to target populations that have been historically challenging to recruit for research. The use of social media influencers in the

diabetes online community as partners and broadcasters to recruit others is a particularly innovative approach to access this hard-to-reach population (Wentzell, Walker, Hughes, & Vessey, 2021).

Clinical Implications

This program of research has the potential to inform the understanding of the emotional burden of living with T1D as an emerging adult by being able to measure it, within this developmental context, for the first time. If the developmentally embedded emotional work of living with T1D during emerging adulthood is not measured accurately, there remains little hope of understanding why this age group experiences worse outcomes than other age groups. Thus, it is critical to be able to accurately capture and describe the emotional work of T1D during emerging adulthood first so that clinicians and researchers can proceed to the next crucial step of improving outcomes.

Additionally, reliable and valid measurement is critical in the continually evolving healthcare marketplace. One of the Affordable Care Act's primary goals was to improve the quality of healthcare by beginning to transition from a reimbursement model that compensates for quantity to a model that compensates for quality of care (Goudreau & Smolenski, 2018; Mason, Gardner, Outlaw, & O'Grady, 2016). This shift from fee-for-service structure to payment for comprehensive patient-centered care requires patient reported outcome measures (PROM) that can accurately assess the quality of care. Though the defined quality outcomes vary by care type and, at the moment, most PROM is limited to measures of patient satisfaction, this emphasis on measurement sets the stage for the use of a more diverse as well as disease-specific sets of PROM to be tied to reimbursement. Therefore, reliable and valid measures are critical to the future of healthcare, and even more specifically, if we cannot measure the emotional burden of living with T1D as an emerging adult, we cannot accurately capture the full complexity of the quality clinical care that is provided.

In addition, this program of research highlights the need for clinicians, research, administrators and policy makers to recognize emerging adulthood as a distinct developmental stage to be able to provide quality care for those often lost in between the pediatric and adult world (Anderson & Wolpert, 2004; Hanna et al., 2014). There has been extensive research on the transition from pediatric diabetes care to adult diabetes care with little consensus on how exactly to navigate it successfully (Saylor et al., 2015; Schultz & Smaldone, 2017). Yet adopting a developmental perspective that transcends the schism between pediatric and adult healthcare helps ground emerging adults in a healthcare home that understands them and is a vital way to increase access (Kullgren et al., 2012; Wagner et al., 2015). So, by designing a measure of DD in emerging adults, the goal is to change the clinical conversation to highlight and prioritize the developmentally embedded emotional burden of T1D to influence current diabetes management both today and in the future.

Future Research

It will remain important to further confirm the validity of the PAID-EA after the tumult of 2020, as well as with a more gender equivalent population, potentially using an in-person recruitment strategy to avoid the limitations of social media. Any new measure requires testing and re-testing to confirm validity with the passage of time, but it will be critical to continue evaluation to further understand the impact of this historical context. As a next step, additional research is needed to identify the ideal scoring approach and to develop clinically useful threshold scores to facilitate use in guiding clinical care. Then the PAID-EA can be tested for responsiveness and ultimately be used to assess the impact of interventions designed to improve diabetes outcomes in emerging adulthood.

Conclusion

This body of research demonstrates that the PAID-EA holds great promise as a reliable, valid and developmentally embedded measure of DD in emerging adults. The PAID-EA will advance the science of measurement of the emotional burden of T1D for both clinical and research use to contribute to changing the health trajectory of emerging adults with T1D.

Cumulative References

Abdoli, S., Hardy, L. R., & Hall, J. (2017). The complexities of "Struggling to live life:" The experiences of young adults with T1DM living in Appalachia. *Diabetes Educator*, 43(2), 206-215. doi:10.1177/0145721717697245

Albanese-O'Neill, A., Beauchamp, G., Thomas, N., Westen, S. C., Johnson, N., Schatz, D., & Haller, M. J. (2018). Transition education for young adults with type 1 diabetes: Pilot feasibility study for a group telehealth intervention. *Journal of Medical Internet Research*, 20(11). doi:10.2196/10909

- American Diabetes Association. (2020). Standards of Medical Care in Diabetes-2020. *Diabetes Care*, S1-S212.
- American Diabetes Association. (2021). Standards of Medical Care in Diabetes-2021. *Diabetes Care*, S1-S232.
- Anderson, B. J., & Wolpert, H. A. (2004). A developmental perspective on the challenges of diabetes education and care during the young adult period. *Patient Education & Counseling*, 53(3), 347-352. doi:10.1016/j.pec.2003.03.001
- Andrich, D. (1978). A rating formulation for ordered response categories. *Psychometrika*, 43(4), 561-573. doi:10.1007/BF02293814
- Antisdel, J. E. (2000). *Diabetes-specific distress among parents of youth with type 1 diabetes*. Yeshiva University, ProQuest Dissertations and Theses. Retrieved from <u>https://search-proquest-com.proxy.bc.edu/docview/304640476?accountid=9673 (9995992)</u>
- Arnett, J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469-480.

- Arnett, J. (2015). *Emerging adulthood: The winding road from the late teens through the twenties* (2nd ed.). New York, NY: Oxford University Press.
- Arnett, J., Kloep, M., Hendry, L., & Tanner, J. (2011). Debating emerging adulthood: stage or process? New York: Oxford University Press.
- Bakhach, M., Reid, M. W., Pyatak, E. A., Berget, C., Cain, C., Thomas, J. F., . . . Raymond, J. K. (2019). Home telemedicine (CoYoT1 Clinic): A novel approach to improve psychosocial outcomes in young adults with diabetes. *Diabetes Educator*, 45(4), 420-430. doi:10.1177/0145721719858080
- Balfe, M., Doyle, F., Smith, D., Sreenan, S., Brugha, R., Hevey, D., & Conroy, R. (2013). What's distressing about having type 1 diabetes? A qualitative study of young adults' perspectives. *BMC Endocrine Disorders*, 13, 25-39. doi:10.1186/1472-6823-13-25
- Bartlett, M. S. (1954). A note on the multiplying factors for various χ2 approximations. *Journal of the Royal Statistical Society. Series B, Methodological, 16*(2), 296-298.
 doi:10.1111/j.2517-6161.1954.tb00174.x
- Baucom, K. J. W., Turner, S. L., Tracy, E. L., Berg, C. A., & Wiebe, D. J. (2018). Depressive symptoms and diabetes management from late adolescence to emerging adulthood. *Health Psychology*, 37(8), 716-724. doi:10.1037/hea0000645
- Bender, J. L., Cyr, A. B., Arbuckle, L., & Ferris, L. E. (2017). Ethics and privacy implications of using the internet and social media to recruit participants for health research: A privacy-by-design framework for online recruitment. *Journal of Medical Internet Research*, *19*(4), e104-e104. doi:10.2196/jmir.7029
- Berg, C. A., Wiebe, D. J., Suchy, Y., Turner, S. L., Butner, J., Munion, A., . . . Murray, M.(2018). Executive function predicting longitudinal change in type 1 diabetes management

during the transition to emerging adulthood. *Diabetes Care, 41*(11), 2281-2288. doi:10.2337/dc18-0351

- Blanchette, J., Toly, V., & Wood, J. (2019). The prevalence of cost-related self-management barriers in emerging adults with T1DM. *The Diabetes Educator*, 45(4), 450-453. doi:10.1177/0145721719858283
- Blanchette, J., Toly, V. B., Wood, J. R., Musil, C. M., Morris, D. L., & Votruba, M. E. (2020).
 Financial stress factors, psychological factors, and self-management outcomes in emerging adults with type 1 diabetes. *Diabetes, 69*(Supplement 1), 817. doi:10.2337/db20-817-P
- Bort, R., & Aleah, K. (2020, December 14). Year in review: How Black Lives Matter inspired a new generation of youth activists. Retrieved from <u>https://www.rollingstone.com/politics/politics-features/black-lives-matter-protests-new-generation-youth-activists-1099895/</u>
- Briggs, S. R., & Cheek, J. M. (1986). The role of factor analysis in the development and evaluation of personality scales. *Journal of personality*, 54(1), 106-148. doi:10.1111/j.1467-6494.1986.tb00391.x
- Bryden, K. S., Dunger, D. B., Mayou, R. A., Peveler, R. C., & Neil, H. A. W. (2003). Poor prognosis of young adults with type 1 diabetes: A longitudinal study. *Diabetes Care*, 26(4), 1052-1057. doi:10.2337/diacare.26.4.1052
- Byrne, M., O'Connell, A., Egan, A. M., Dinneen, S. F., Hynes, L., O'Hara, M. C., ... Coyne, I. (2017). A core outcomes set for clinical trials of interventions for young adults with type 1 diabetes: An international, multi-perspective Delphi consensus study. *Trials, 18*(1). doi:10.1186/s13063-017-2364-y

- Cabassa, L. J., Hansen, M. C., Palinkas, L. A., & Ell, K. (2008). Azúcar y nervios: Explanatory models and treatment experiences of Hispanics with diabetes and depression. *Social Science and Medicine*, 66(12), 2413.
- Calamaro, C. J., Saylor, J., & Hanna, K. M. (2018). Health care experience of young adults diagnosed with type 1 diabetes. *Journal for Nurse Practitioners*, 14(6), 484-490. doi:10.1016/j.nurpra.2018.02.002
- Carlsund, A., & Soderberg, S. (2019). Living with type 1 diabetes as experienced by young adults. *Nursing Open, 6*(2), 418-425. doi:10.1002/nop2.222
- Catell, R. B. (1966). The scree test for number of factors. *Multivariate Behavioral Research*, *1*, 245-276.
- Center for Disease Control and Prevention. (2020). National diabetes statistics report 2020. Retrieved from <u>https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf</u>
- Chinn, P. L., & Kramer, M. K. (2008). *Integrated theory and knowledge development in nursing* (7th ed.. ed.). St. Louis: Mosby Elsevier.
- Choi, I., Milne, D. N., Glozier, N., Peters, D., Harvey, S. B., & Calvo, R. A. (2017). Using different Facebook advertisements to recruit men for an online mental health study: Engagement and selection bias. *Internet Interventions*, 8(C), 27-34. doi:10.1016/j.invent.2017.02.002
- Clarke, J., Proudfoot, J., Vatiliotis, V., Verge, C., Holmes-Walker, D. J., Campbell, L., . . . Bridgett, M. (2018). Attitudes towards mental health, mental health research and digital interventions by young adults with type 1 diabetes: A qualitative analysis. *Health Expectations*, 21(3), 668-677. doi:10.1111/hex.12662

- Clausi, L., & Schneider, M. (2017). "...Part of My Identity": The impact of self-management on the sense of self of young women with type 1 diabetes. *Clinical Nurse Specialist: The Journal for Advanced Nursing Practice, 31*(2), 97-103. doi:10.1097/nur.0000000000280
- Collins, S., & Nicholson, J. (2010). *Rite of passage: Young adults and the Affordable Care Act of 2010*. Retrieved from https://www.commonwealthfund.org/sites/default/files/documents/ media files public

ations_issue_brief_2010_may_1404_collins_rite_of_passage_2010_v3.pdf

- Creswell, J. W., & Creswell, J. D. (2018). Research design: qualitative, quantitative, and mixed methods approaches (Fifth edition.. ed.). Thousand Oaks, California: SAGE Publications, Inc.
- Dabelea, D., Mayer-Davis, E. J., Saydah, S., Imperatore, G., Linder, B., Divers, J., . . . Talton, J. (2014). Prevalence of type 1 and type 2 diabetes among children and adolescents from 2001 to 2009. *Journal of the American Medical Association*, *311*(17), 1778-1786. doi:10.1001/jama.2014.3201
- Dennick, K., Sturt, J., & Speight, J. (2017). What is diabetes distress and how can we measure it? A narrative review and conceptual model. *Journal of Diabetes and its Complications*, *31*(5), 898-911. doi:10.1016/j.jdiacomp.2016.12.018
- Dickinson, J. K. (2018). The experience of diabetes-related language in diabetes care. *Diabetes* Spectrum, 31(1), 58-64. doi:10.2337/ds16-0082
- Dickinson, J. K., Guzman, S. J., Maryniuk, M. D., O'Brian, C. A., Kadohiro, J. K., Jackson, R.
 A., . . . Funnell, M. M. (2017). The use of language in diabetes care and education. *Diabetes Care, 40*(12), 1790-1799. doi:10.2337/dci17-0041

- Dijk, S., Adriaanse, M., Zwaan, L., Bosmans, J., Marwijk, H., Tulder, M., & Terwee, C. (2018).
 Measurement properties of depression questionnaires in patients with diabetes: a systematic review. *An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 27(6), 1415-1430. doi:10.1007/s11136-018-1782-y
- Dillman, D. A., Smyth, J. D., & Christian, L. M. (2014). *Internet, phone, mail, and mixed-mode surveys: the tailored design method* (Fourth edition.. ed.). Hoboken, New Jersey: Wiley.
- Donaldson, S., & Crowley, D. (1978). The Discipline of Nursing. *Nursing Outlook, 26*(2), 113-120.
- Downie, G. A., Mullan, B. A., Boyes, M. E., & McEvoy, P. M. (2019). The effect of psychological distress on self-care intention and behaviour in young adults with type 1 diabetes. *Journal of Health Psychology*. doi:10.1177/1359105318824795
- Ellis, L. A., Collin, P., Davenport, T. A., Hurley, P. J., Burns, J. M., & Hickie, I. B. (2012).
 Young men, mental health, and technology: Implications for service design and delivery in the digital age. *Journal of Medical Internet Research*, *14*(6), e160-e160.
 doi:10.2196/jmir.2291
- Ellis, L. A., Collin, P., Hurley, P. J., Davenport, T. A., Burns, J. M., & Hickie, I. B. (2013).
 Young men's attitudes and behaviour in relation to mental health and technology:
 implications for the development of online mental health services. *BMC Psychiatry*, *13*(1), 119-119. doi:10.1186/1471-244X-13-119

Erikson, E. H. (1963). Childhood and society (2d ed., rev. and enl.. ed.). New York: Norton.

Ersig, A. L. (2019). An exploratory study: Transition to adulthood for college students with type
1 diabetes and their parents. *Journal of Pediatric Nursing*, 46, 12-17.
doi:10.1016/j.pedn.2019.01.008

- Evans, M. A., Weil, L. E. G., Shapiro, J. B., Anderson, L. M., Vesco, A. T., Rychlik, K., . . .
 Weissberg-Benchell, J. (2019). Psychometric properties of the Parent and Child Problem
 Areas in Diabetes measures. *Journal of Pediatric Psychology*, 44(6), 703-713.
 doi:10.1093/jpepsy/jsz018
- Fawcett, J., Watson, J., Neuman, B., & Hinton, P. (2001). On nursing theories and evidence. *Journal of Nursing Scholarship*, 33(2), 115-119. doi:10.1111/j.1547-5069.2001.00115.x
- Fergie, G., Hunt, K., & Hilton, S. (2016). Social media as a space for support: Young adults' perspectives on producing and consuming user-generated content about diabetes and mental health. *Social Science and Medicine*, 170, 46-54. doi:10.1016/j.socscimed.2016.10.006
- Fisher, L., Gonzalez, J. S., & Polonsky, W. H. (2014). The confusing tale of depression and distress in patients with diabetes: A call for greater clarity and precision. *Diabetic Medicine*, 31(7), 764-772. doi:10.1111/dme.12428
- Fisher, L., Hessler, D., Polonsky, W., Strycker, L., Guzman, S., Bowyer, V., . . . Masharani, U. (2018). Emotion regulation contributes to the development of diabetes distress among adults with type 1 diabetes. *Patient Education and Counseling*, *101*(1), 124-131. doi:10.1016/j.pec.2017.06.036
- Fisher, L., Hessler, D., Polonsky, W. H., Masharani, U., Guzman, S., Bowyer, V., ... Wu, P.
 (2018). T1-REDEEM: A randomized controlled trial to reduce diabetes distress among adults with type 1 diabetes. *Diabetes Care, 41*(9), 1862-1869. doi:10.2337/dc18-0391
- 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. *Diabetes Care*, 35(2), 259-264. doi:10.2337/dc11-1572

- Forsander, G., Bogelund, M., Haas, J., & Samuelsson, U. (2017). Adolescent life with diabetes-Gender matters for level of distress. Experiences from the national TODS study. *Pediatric Diabetes*, *18*(7), 651-659. doi:10.1111/pedi.12478
- Foster, N. C., Beck, R. W., Miller, K. M., Clements, M. A., Rickels, M. R., DiMeglio, L. A., . . .
 Garg, S. K. (2019). State of type 1 diabetes management and outcomes from the T1D
 Exchange in 2016-2018. *Diabetes Technology & Therapeutics, 21*(2), 66-72.
 doi:10.1089/dia.2018.0384
- Franzke, A. S., Bechmann, A., Zimmer, M., Ess, C., & The Association of Internet Researchers. (2020). Internet Research: Ethical Guidelines 3.0. Retrieved from <u>https://aoir.org/reports/ethics3.pdf</u>
- Fredette, J., Mawn, B., Hood, K., & Fain, J. (2016). Quality of life of college students living with type 1 diabetes: A qualitative view. *Western Journal of Nursing Research*, 38(12), 1595-1610. doi:10.1177/0193945916651265
- Fry, R., Passel, J., & Cohn, D. (2020, September 4). A majority of young adults in the U.S. live with their parents for the first time since the Great Depression. *Fact Tank: News in the numbers*. Retrieved from <u>https://www.pewresearch.org/fact-tank/2020/09/04/a-majority-of-young-adults-in-the-u-s-live-with-their-parents-for-the-first-time-since-the-greatdepression/</u>
- Galea, S., & Tracy, M. (2007). Participation rates in epidemiologic studies. *Annals of Epidemiology*, *17*(9), 643-653. doi:10.1016/j.annepidem.2007.03.013
- Garvey, K. C., Foster, N. C., Agarwal, S., DiMeglio, L. A., Anderson, B. J., Corathers, S. D., . . . Laffel, L. M. (2017). Health care transition preparation and experiences in a U.S. national

sample of young adults with type 1 diabetes. *Diabetes Care*, 40(3), 317-324. doi:10.2337/dc16-1729

- Garza, K. P., Weil, L. E. G., Anderson, L. M., Naranjo, D., Barnard-Kelly, K. D., Laffel, L., . . .
 Weissberg-Benchell, J. (2020). You, me, and diabetes: Intimacy and technology among adults with T1D and their partners. *Families Systems & Health*, 38(4), 418-427. doi:10.1037/fsh0000485
- Gelinas, L., Pierce, R., Winkler, S., Cohen, I. G., Lynch, H. F., & Bierer, B. E. (2017). Using social media as a research recruitment tool: Ethical issues and recommendations.
 American Journal of Bioethics, 17(3), 3-14. doi:10.1080/15265161.2016.1276644
- Gemma, V., Carlos, G. F., Gabriela, B., & Jordi, A. (2016). Screening for depression in the general population with the Center for Epidemiologic Studies Depression (CES-D): A systematic review with meta-analysis. *PLoS ONE*, *11*(5), e0155431.
 doi:10.1371/journal.pone.0155431
- Gonzalez, J., Fisher, L., & Polonsky, W. (2011). Depression in diabetes: Have we been missing something important? *Diabetes Care, 34*(11), 2488-2488. doi:10.2337/dc10-1970
- Goudreau, K. A., & Smolenski, M. C. (2018). Health policy and advanced practice nursing : impact and implications (Second edition.. ed.). New York, NY: Springer Publishing Company, LLC.
- Grace, P. J., & Perry, J. D. (2013). Philosophical inquiry and the goals of nursing: A critical approach for disciplinary knowledge development and action. *Advances in Nursing Science*, 36(2), 64-79. doi:10.1097/ANS.0b013e3182901921

- Grace, P. J., & Willis, D. G. (2012). Nursing responsibilities and social justice: An analysis in support of disciplinary goals. *Nursing Outlook*, 60(4), 198-207.
 doi:10.1016/j.outlook.2011.11.004
- Hagger, V., Hendrieckx, C., Cameron, F., Pouwer, F., Skinner, T. C., & Speight, J. (2018).
 Diabetes distress is more strongly associated with HbA1c than depressive symptoms in adolescents with type 1 diabetes: Results from Diabetes MILES Youth-Australia. *Pediatric Diabetes, 19*(4), 840-847. doi:10.1111/pedi.12641
- Hagger, V., Hendrieckx, C., Sturt, J., Skinner, T., & Speight, J. (2016). Diabetes distress among adolescents with type 1 diabetes: A systematic review. *Current Diabetes Reports*, 16(1), 1-14. doi:10.1007/s11892-015-0694-2
- Hanna, K. M., Scott, L. L., & Schmidt, K. K. (2014). Retention strategies in longitudinal studies with emerging adults. *Clinical Nurse Specialist*, 28(1), 41-45.
 doi:10.1097/NUR.0000000000000020
- Helgeson, V. S., Vaughn, A. K., Seltman, H., Orchard, T., Libman, I., & Becker, D. (2018).
 Trajectories of glycemic control over adolescence and emerging adulthood: An 11-year longitudinal study of youth with type 1 diabetes. *Journal of Pediatric Psychology, 43*(1), 8-18. doi:10.1093/jpepsy/jsx083
- Hermann, J. M., Miller, K. M., Hofer, S. E., Clements, M. A., Karges, W., Foster, N. C., . . .
 Maahs, D. M. (2020). The Transatlantic HbA1c gap: differences in glycaemic control across the lifespan between people included in the US T1D Exchange Registry and those included in the German/Austrian DPV registry. *Diabetic Medicine*, *37*(5), 848-855. doi:10.1111/dme.14148

- Hermanns, N., Kulzer, B., Krichbaum, M., Kubiak, T., & Haak, T. (2006). How to screen for depression and emotional problems in patients with diabetes: comparison of screening characteristics of depression questionnaires, measurement of diabetes-specific emotional problems and standard clinical assessment. *Clinical and Experimental Diabetes and Metabolism*, 49(3), 469-477. doi:10.1007/s00125-005-0094-2
- Hessler, D. M., Fisher, L., Polonsky, W. H., Masharani, U., Strycker, L. A., Peters, A. L., ...
 Bowyer, V. (2017). Diabetes distress is linked with worsening diabetes management over time in adults with type 1 diabetes. *Diabetic Medicine*, *34*(9), 1228-1234.
 doi:10.1111/dme.13381
- Hilliard, M. E., De Wit, M., Wasserman, R. M., Butler, A. M., Evans, M., Weissberg-Benchell,
 J., & Anderson, B. J. (2018). Screening and support for emotional burdens of youth with
 type 1 diabetes: Strategies for diabetes care providers. *Pediatric Diabetes*, *19*(3), 534543. doi:10.1111/pedi.12575
- Horn, J. L. (1965). A rationale and test for the number of factors in factor analysis. *Psychometrika*, 30, 179-185.
- IBMCorp. (2020). IBM SPSS Statistics for Windows (Version 27). Armonk, NY: IBMCorp.
- Iturralde, E., Rausch, J. R., Weissberg-Benchell, J., & Hood, K. K. (2019). Diabetes-Related Emotional Distress Over Time. *Pediatrics*, *143*(6). doi:10.1542/peds.2018-3011
- James, S., Gallagher, R., Dunbabin, J., & Perry, L. (2014). Prevalence of vascular complications and factors predictive of their development in young adults with type 1 diabetes:
 Systematic literature review. *BMC Research Notes*, 7(1), 593-604. doi:10.1186/1756-0500-7-593

- Jaser, S. S., Lord, J. H., Savin, K., Gruhn, M., & Rumburg, T. (2018). Developing and testing an intervention to reduce distress in mothers of adolescents with type 1 diabetes. *Clinical Practice in Pediatric Psychology*, 6(1), 19. doi:10.1037/cpp0000220
- Jeffrey, A. B., Kevan, H., & George, E. (2010). Genetics, pathogenesis and clinical interventions in type 1 diabetes. *Nature*, *464*(7293), 1293-1300. doi:10.1038/nature08933
- Jeong, Y. M., Quinn, L., Kim, N., & Martyn-Nemeth, P. (2018). Health-related stigma in young adults with type 1 diabetes mellitus. *Journal of Psychosocial Nursing and Mental Health Services*, 56(10), 44-51. doi:10.3928/02793695-20180503-01
- Joensen, L. E., Madsen, K. P., Holm, L., Nielsen, K. A., Rod, M. H., Petersen, A. A., . . .
 Willaing, I. (2020). Diabetes and COVID-19: psychosocial consequences of the COVID-19 pandemic in people with diabetes in Denmark—what characterizes people with high levels of COVID-19-related worries? *Diabetic Medicine*, *37*(7), 1146-1154. doi:10.1111/dme.14319
- Joensen, L. E., Tapager, I., & Willaing, I. (2013). Diabetes distress in type 1 diabetes—a new measurement fit for purpose. *Diabetic Medicine*, 30(9), 1132-1139. doi:10.1111/dme.12241
- Johnson, B., Eiser, C., Young, V., Brierley, S., & Heller, S. (2013). Prevalence of depression among young people with type 1 diabetes: A systematic review. *Diabetic Medicine*, 30(2), 199-208. doi:10.1111/j.1464-5491.2012.03721.x
- Kaiser, H. (1970). A second generation little jiffy. *Psychometrika*, 35(4), 401-415. doi:10.1007/BF02291817
- Kaiser, H. (1974). An index of factorial simplicity. *Psychometrika*, *39*(1), 31-36. doi:10.1007/BF02291575

- Kalra, S., Verma, K., & Balhara, Y. (2018). Diabetes distress. *Journal of Social Health and Diabetes*, 6(1), 4-7. doi:10.4103/JSHD_JSHD_22_17
- Kullgren, J. T., McLaughlin, C. G., Mitra, N., & Armstrong, K. (2012). Nonfinancial barriers and access to care for U.S. adults. *Health Services Research*, 47(1pt2), 462-485. doi:10.1111/j.1475-6773.2011.01308.x
- Lasaite, L., Dobrovolskiene, R., Danyte, E., Stankute, I., Razanskaite-Virbickiene, D.,
 Schwitzgebel, V., . . . Verkauskiene, R. (2016). Diabetes distress in males and females
 with type 1 diabetes in adolescence and emerging adulthood. *Journal of Diabetes and its Complications, 30*(8), 1500-1505. doi:10.1016/j.jdiacomp.2016.08.013
- Lasaite, L., Ostrauskas, R., Zalinkevicius, R., Jurgeviciene, N., & Radzeviciene, L. (2016).
 Diabetes distress in adult type 1 diabetes mellitus men and women with disease onset in childhood and in adulthood. *Journal of Diabetes and its Complications, 30*(1), 133-137. doi:10.1016/j.jdiacomp.2015.09.012
- Lawrence, J. M., Standiford, D. A., Loots, B., Klingensmith, G. J., Williams, D. E., Ruggiero,
 A., . . . McKeown, R. E. (2006). Prevalence and correlates of depressed mood among
 youth with diabetes: the SEARCH for Diabetes in Youth study. *Pediatrics*, *117*(4), 1348.
 doi:10.1542/peds.2005-1398
- Lerman-Garber, I., Barrón-Uribe, C., Calzada-León, R., Mercado-Atri, M., Vidal-Tamayo, R.,
 Quintana, S., . . . Villa, A. R. (2003). Emotional dysfunction associated with diabetes in
 Mexican adolescents and young adults with type 1 diabetes. *Salud Pública de México*,
 45(1), 13-18. doi:10.1590/S0036-36342003000100002
- Linacre, J. M. (2020a). Help for Winsteps Rasch measurement and Rasch analysis software. Retrieved from <u>www.winsteps.com</u>

- Linacre, J. M. (2020b). Winsteps® Rasch measurement computer program. Beaverton, OR: Winsteps.com.
- Litchman, M. L., Oser, T. K., Hodgson, L., Heyman, M., Walker, H. R., Deroze, P., . . .
 Warshaw, H. (2020). In-person and technology-mediated peer support in diabetes care: A systematic review of reviews and gap analysis. *Diabetes Educator, 46*(3), 230-241. doi:10.1177/0145721720913275
- Lloyd, C. E., Pambianco, G., & Orchard, T. J. (2010). Does diabetes-related distress explain the presence of depressive symptoms and/or poor self-care in individuals with type 1 diabetes? *Diabetic Medicine*, 27(2), 234. doi:10.1111/j.1464-5491.2009.02896.x
- Ludlow, L. H. (1985). A strategy for the graphical representation of Rasch model residuals. *Educational and Psychological Measurement, 45*, 851-859.
- Luyckx, K., Rassart, J., Aujoulat, I., Goubert, L., & Weets, I. (2016). Self-esteem and illness self-concept in emerging adults with type 1 diabetes: Long-term associations with problem areas in diabetes. *Journal of Health Psychology*, 21(4), 540-549. doi:10.1177/1359105314531467
- Luyckx, K., Rassart, J., & Weets, I. (2015). Illness self-concept in type 1 diabetes: A crosssectional view on clinical, demographic, and psychosocial correlates. *Psychology, Health* & *Medicine, 20*(1), 77-86. doi:10.1080/13548506.2014.902482
- Lysaght, Z., O'Leary, M., & Ludlow, L. (2017). Measuring teachers' assessment for learning (AfL) classroom practices in elementary schools. *International Journal of Educational Methodology*, 3(2), 103-115. doi:10.12973/ijem.3.2.103
- Markowitz, B., Pritlove, C., Mukerji, G., Lavery, J. V., Parsons, J. A., & Advani, A. (2019). The 3i conceptual framework for recognizing patient perspectives of type 1 diabetes during

emerging adulthood. JAMA Network Open, 2(7), e196944.

doi:10.1001/jamanetworkopen.2019.6944

- Markowitz, J., Volkening, L. K., Butler, D. A., Antisdel-Lomaglio, J., Anderson, B. J., & Laffel, L. M. (2012). Re-examining a measure of diabetes-related burden in parents of young people with type 1 diabetes: the Problem Areas in Diabetes Survey Parent Revised version (PAID-PR). *Diabetic Medicine, 29*(4), 526-530. doi:10.1111/j.1464-5491.2011.03434.x
- Markowitz, J., Volkening, L. K., Butler, D. A., & Laffel, L. M. (2015). Youth-perceived burden of type 1 diabetes: Problem Areas in Diabetes survey-Pediatric Version (PAID-Peds). *Journal of Diabetes Science and Technology*, 9(5), 1080-1085. doi:10.1177/1932296815583506
- Mason, D. J., Gardner, D. B., Outlaw, F. H., & O'Grady, E. T. (2016). Policy & politics in nursing and health care (Seventh edition.. ed.). St. Louis, Missouri: Elsevier.
- Mayer-Davis, E. J., Lawrence, J. M., Dabelea, D., Divers, J., Isom, S., Dolan, L., . . .
 Wagenknecht, L. (2017). Incidence trends of type 1 and type 2 diabetes among youths, 2002-2012. *The New England Journal of Medicine, 376*(15), 1419-1429. doi:10.1056/NEJMoa1610187
- McCarthy, M. M., & Grey, M. (2018). Type 1 diabetes self-management: From emerging adulthood through older adulthood. *Diabetes Care*, 41(8), 1608-1614. doi:10.2337/dc17-2597
- McGuire, B. E., Morrison, T. G., Hermanns, N., Skovlund, S., Eldrup, E., Gagliardino, J., . . . Snoek, F. J. (2010). Short-form measures of diabetes-related emotional distress: the

Problem Areas in Diabetes Scale (PAID)-5 and PAID-1. *Diabetologia*, *53*(1), 66-69. doi:10.1007/s00125-009-1559-5

- Monaghan, M., Helgeson, V., & Wiebe, D. (2015). Type 1 diabetes in young adulthood. *Current Diabetes Reviews*, 11(4), 239-250. doi:10.2174/1573399811666150421114957
- Nathan, D., Cleary, P. A., Backlund, J.-Y. C., Genuth, S. M., Lachin, J. M., Orchard, T. J., ...
 Zinman, B. (2005). Intensive diabetes treatment and cardiovascular disease in patients
 with type 1 diabetes. *The New England Journal of Medicine*, *353*(25), 2643-2653.
 doi:10.1056/NEJMoa052187
- Nathan, D., Genuth, S., Lachin, J., Cleary, P., Crofford, O., Davis, M., . . . Nathan, D. M. (1993). The effect of intensive treatment of diabetes on the development and progression of longterm complications in insulin-dependent diabetes mellitus. *The New England Journal of Medicine*, 329(14), 977-986. doi:10.1056/NEJM199309303291401
- Nicolucci, A., Kovacs Burns, K., Holt, R. I., Comaschi, M., Hermanns, N., Ishii, H., . . . Group,
 D. S. (2013). Diabetes Attitudes, Wishes and Needs second study (DAWN2): crossnational benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabetic Medicine*, 30(7), 767-777. doi:10.1111/dme.12245
- Northam, E. A., Lin, A., Finch, S., Werther, G. A., & Cameron, F. J. (2010). Psychosocial wellbeing and functional outcomes in youth with type 1 diabetes 12 years after disease onset. *Diabetes Care*, 33(7), 1430. doi:10.2337/dc09-2232

Nunnally, J. C. (1978). Psychometric theory (2d ed.. ed.). New York: McGraw-Hill.

O'Hara, M. C., Hynes, L., O'Donnell, M., Nery, N., Byrne, M., Heller, S. R., . . . the Irish Type 1 Diabetes Young Adult Study, G. (2017). A systematic review of interventions to improve outcomes for young adults with type 1 diabetes. *Diabetic Medicine*, *34*(6), 753-769. doi:10.1111/dme.13276

- Oris, L., Luyckx, K., Rassart, J., Goethals, E., Bijttebier, P., Goubert, L., . . . Weets, I. (2016).
 Change and stability in depressive symptoms in young adults with type 1 diabetes. *Diabetes Research & Clinical Practice*, 111, 93-96. doi:10.1016/j.diabres.2015.10.023
- Oser, T. K., Oser, S. M., Parascando, J. A., Hessler-Jones, D., Sciamanna, C. N., Sparling, K., . .
 Litchman, M. L. (2020). Social media in the diabetes community: A novel way to assess psychosocial needs in people with diabetes and their caregivers. *Current Diabetes Reports, 20*(3), 10-10. doi:10.1007/s11892-020-1294-3
- Patel, N. J., Datye, K. A., & Jaser, S. S. (2018). Importance of patient-provider communication to adherence in adolescents with type 1 diabetes. *Healthcare*, 6(2). doi:10.3390/healthcare6020030
- Perrin, N. E., Davies, M. J., Robertson, N., Snoek, F. J., & Khunti, K. (2017). The prevalence of diabetes-specific emotional distress in people with type 2 diabetes: a systematic review and meta-analysis. *Diabetic Medicine*, 34(11), 1508-1520.
- Peters, A., Laffel, L., & American Diabetes Association Transitions Working Group. (2011).
 Diabetes care for emerging adults: Recommendations for transition from pediatric to adult diabetes care systems. A position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children with Diabetes, The Endocrine Society, the International Society for Pediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the

National Diabetes Education Program, and the Pediatric Endocrine Society (formerly Lawson Wilkins Pediatric Endocrine Society). *Diabetes Care, 34*(11), 2477-2485. doi:10.2337/dc11-1723

- Pettus, J. H., Zhou, F. L., Shepherd, L., Preblick, R., Hunt, P. R., Paranjape, S., . . . Edelman, S. V. (2019). Incidences of severe hypoglycemia and diabetic ketoacidosis and prevalence of microvascular complications stratified by age and glycemic control in U.S. adult patients with type 1 diabetes: A real world study. *Diabetes Care, 42*(12), 2220-2227. doi:10.2337/dc19-0830
- Pew Research Center. (2019). Social Media Fact Sheet. Retrieved from https://www.pewresearch.org/internet/fact-sheet/social-media/
- Peyrot, M., & Rubin, R. (1997). Levels and risks of depression and anxiety symptomatology among diabetic adults. *Diabetes Care, 20*(4), 585-590.
- Pinhas-Hamiel, O., Tisch, E., Levek, N., Ben-David, R. F., Graf-Bar-El, C., Yaron, M., . . . Lerner-Geva, L. (2017). Sexual lifestyle among young adults with type 1 diabetes. *Diabetes Metab Res Rev, 33*(2), n/a. doi:10.1002/dmrr.2837
- Polonsky, W., Anderson, B., Lohrer, P., Welch, G., Jacobson, A., Aponte, J., & Schwartz, C. (1995). Assessment of diabetes-related distress. *Diabetes Care, 18*(6), 754-760. doi:10.2337/diacare.18.6.754 %J Diabetes Care
- Polonsky, W., Fisher, L., Earles, J., Dudl, R. J., Lees, J., Mullan, J., & Jackson, R. A. (2005).
 Assessing psychosocial distress in diabetes: Development of the Diabetes Distress Scale.
 Diabetes Care, 28(3), 626-631. doi:10.2337/diacare.28.3.626
- Pozzar, R., Hammer, M. J., Underhill-Blazey, M., Wright, A. A., Tulsky, J. A., Hong, F., . . . Berry, D. L. (2020). Threats of bots and other bad actors to data quality following

research participant recruitment through social media: Cross-sectional questionnaire. Journal of Medical Internet Research, 22(10), e23021-e23021. doi:10.2196/23021

Qualtrics. (2005). Qualtrics. Retrieved from <u>www.qualtrics.com</u>

- Quinn, S. M., Ambrosino, J. M., Doyle, E. A., Weyman, K., Tamborlane, W. V., & Jastreboff,
 A. M. (2016). Utility of psychological screening of young adults with type 1 diabetes
 transitioning to adult providers. *Endocrine Practice*, 22(9), 1104-1110.
 doi:10.4158/EP151190.OR
- Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1(3), 385-401.
 doi:10.1177/014662167700100306
- Ramchandani, N., Way, N., Melkus, G. D., & Sullivan-Bolyai, S. (2019). Challenges to diabetes self-management in emerging adults with type 1 diabetes. *Diabetes Educator*, 45(5), 484-497. doi:10.1177/0145721719861349
- Rasch, G. (1960). *Probabilistic models for some intelligence and attainment tests*. Chicago, IL: University of Chicago Press.
- Rassart, Luyckx, K., Berg, C. A., Bijttebier, P., Moons, P., & Weets, I. (2015). Psychosocial functioning and glycemic control in emerging adults with type 1 diabetes: A 5-year follow-up study. *Health Psychology*, 34(11), 1058-1065. doi:10.1037/hea0000212
- Rassart, J., Luyckx, K., Klimstra, T. A., Moons, P., Groven, C., & Weets, I. (2014). Personality and illness adaptation in adults with type 1 diabetes: The intervening role of illness coping and perceptions. *Journal of Clinical Psychology in Medical Settings, 21*(1), 41-55. doi:10.1007/s10880-014-9387-2

- Rassart, J., Luyckx, K., Moons, P., & Weets, I. (2014). Personality and self-esteem in emerging adults with type 1 diabetes. *Journal of Psychosomatic Research*, 76(2), 139-145. doi:10.1016/j.jpsychores.2013.11.015
- Rawshani, A., Sattar, N., Franzén, S., Rawshani, A., Hattersley, A. T., Svensson, A.-M., . . .
 Gudbjörnsdottir, S. (2018). Excess mortality and cardiovascular disease in young adults with type 1 diabetes in relation to age at onset: a nationwide, register-based cohort study. *Lancet*, 392(10146), 477-486. doi:10.1016/s0140-6736(18)31506-x
- Raymaekers, K., Oris, L., Prikken, S., Moons, P., Goossens, E., Weets, I., & Luyckx, K. (2017).
 The role of peers for diabetes management in adolescents and emerging adults with type
 1 diabetes: A longitudinal study. *Diabetes Care, 40*(12), 1678-1684. doi:10.2337/dc17-0643
- Sanders, T., Elliott, J., Norman, P., Johnson, B., & Heller, S. (2018). Experiences of selfmanagement among young adults with type 1 diabetes in the context of a structured education programme: a qualitative study. *Diabetic Medicine*, 35(11), 1531-1537. doi:10.1111/dme.13784
- Saylor, J., Boyle, C., Buck, J., Bean, S., & Aurele, K. (2015). Transition of emerging young adults with type 1 diabetes: An integrative literature review. *Nursing Research*, 64(2), E16-E16.
- Saylor, J., Hanna, K. M., & Calamaro, C. J. (2019). Experiences of college students who are newly diagnosed with type 1 diabetes mellitus. *Journal of Pediatric Nursing*, 44, 74-80. doi:10.1016/j.pedn.2018.10.020
- Schmitt, A., Reimer, A., Kulzer, B., Haak, T., Ehrmann, D., & Hermanns, N. (2016). How to assess diabetes distress: comparison of the Problem Areas in Diabetes Scale (PAID) and
the Diabetes Distress Scale (DDS). *Diabetic Medicine*, 33(6), 835-843.

doi:10.1111/dme.12887

- Schultz, A. T., & Smaldone, A. (2017). Components of interventions that improve transitions to adult care for adolescents with type 1 diabetes. *Journal of Adolescent Health*, 60(2), 133-146. doi:10.1016/j.jadohealth.2016.10.002
- Schwandt, A., Hermann, J. M., Rosenbauer, J., Boettcher, C., Grulich-Henn, J., Dunstheimer, D.,
 ... Holl, R. W. (2017). Longitudinal trajectories of metabolic control from childhood to
 young adulthood in type 1 diabetes from a large German/Austrian registry: A groupbased modeling approach. *Diabetes Care, 40*(3), 309-316. doi:10.2337/dc16-1625
- Shapiro, J. B., Vesco, A. T., Weil, L. E. G., Evans, M. A., Hood, K. K., & Weissberg-Benchell,
 J. (2018). Psychometric properties of the Problem Areas in Diabetes: Teen and Parent of
 Teen Versions. *Journal of Pediatric Psychology*, 43(5), 561-571.
 doi:10.1093/jpepsy/jsx146
- Sherman, N. (2020, October 16). US election 2020: The young people struggling in the 2020 economy. Retrieved from <u>https://www.bbc.com/news/election-us-2020-54471388</u>
- Skinner, T. C., Joensen, L., & Parkin, T. (2019). Twenty-five years of diabetes distress research. *Diabetic Medicine*, 37(3), 393-400. doi:10.1111/dme.14157
- Smith, R. M., Schumacker, R. E., & Bush, M. J. (1998). Using item mean squares to evaluate fit to the Rasch model. *Journal of Outcome Measurement*, 2(1), 66-78.
- Snoek, F. J., Bremmer, M. A., & Hermanns, N. (2015). Constructs of depression and distress in diabetes: time for an appraisal. *The Lancet Diabetes & Endocrinology*, 3(6), 450-460. doi:10.1016/s2213-8587(15)00135-7

- Spaic, T., Robinson, T., Goldbloom, E., Gallego, P., Hramiak, I., Lawson, M. L., . . . Clarson, C. (2019). Closing the gap: Results of the multicenter Canadian randomized controlled trial of structured transition in young adults with type 1 diabetes. *Diabetes Care, 42*(6), 1018-1026. doi:10.2337/dc18-2187
- Stahl-Pehe, A., Glaubitz, L., Bachle, C., Lange, K., Castillo, K., Tonnies, T., . . . Rosenbauer, J. (2019). Diabetes distress in young adults with early-onset type 1 diabetes and its prospective relationship with HbA1c and health status. *Diabetic Medicine*, *36*(7), 836-846. doi:10.1111/dme.13931
- Strandberg, R. B., Graue, M., Wentzel-Larsen, T., Peyrot, M., & Rokne, B. (2014). Relationships of diabetes-specific emotional distress, depression, anxiety, and overall well-being with HbA1c in adult persons with type 1 diabetes. *Journal of Psychosomatic Research*, 77(3), 174-179. doi:10.1016/j.jpsychores.2014.06.015
- Strandberg, R. B., Graue, M., Wentzel-Larsen, T., Peyrot, M., Thordarson, H. B., & Rokne, B. (2015). Longitudinal relationship between diabetes-specific emotional distress and follow-up HbA1c in adults with type 1 diabetes mellitus. *Diabetic Medicine*, 32(10), 1304-1310. doi:10.1111/dme.12781
- Sturt, J., Dennick, K., Due-Christensen, M., & McCarthy, K. (2015). The detection and management of diabetes distress in people with type 1 diabetes. *Current Diabetes Reports*, 15(11), 101. doi:10.1007/s11892-015-0660-z
- Sturt, J., McCarthy, K., Dennick, K., Narasimha, M., Sankar, S., & Kumar, S. (2015). What characterises diabetes distress and its resolution? A documentary analysis. *International Diabetes Nursing*, 12(2), 56-62. doi:10.1179/2057332415y.0000000002

- Tanenbaum, M. L., Hanes, S. J., Miller, K. M., Naranjo, D., Bensen, R., & Hood, K. K. (2017).
 Diabetes device use in adults with type 1 diabetes: Barriers to uptake and potential intervention targets. *Diabetes Care*, 40(2), 181-187. doi:10.2337/dc16-1536
- Tanner, J. L. (2006). Recentering during emerging adulthood: A critical turning point in life span human development. In J. J. Arnett & J. L. Tanner (Eds.), *Emerging adults in America: Coming of age in the 21st century* (pp. 21). Washington, DC: American Psychological Association.
- Tenderich, A., Tenderich, B., Barton, T., & Richards, S. E. (2019). What are PWDs (People With Diabetes) doing online? A netnographic analysis. *Journal of Diabetes Science and Technology*, 13(2), 187-197. doi:10.1177/1932296818813192
- U.S. Census Bureau. (2019). 2014-2018 American Community Survey (ACS) 5-year estimates. Retrieved from <u>https://data.census.gov/cedsci/</u>
- Vallis, M., Willaing, I., & Holt, R. I. G. (2018). Emerging adulthood and type 1 diabetes: Insights from the DAWN2 Study. *Diabetic Medicine*, *35*(2), 203-213. doi:10.1111/dme.13554
- Wagner, D. V., Ulrich, J., Guttmann-Bauman, I., & Duke, D. C. (2015). The process of transition from pediatric to adult diabetes care: Recommendations for US healthcare systems. *Diabetes Management*, 5(5), 379. doi:10.2217/dmt.15.31
- Warshaw, H., Hodgson, L., Heyman, M., Oser, T. K., Walker, H. R., Deroze, P., . . . Litchman,
 M. L. (2019). The role and value of ongoing and peer support in diabetes care and
 education. *Diabetes Educator*, 45(6), 569-579. doi:10.1177/0145721719882007
- Weiss, S. (1995). Contemporary empiricism. In A. Omery, C. Kasper, & G. Page (Eds.), In search of nursing science (pp. 13-26). Thousan Oaks, CA: SAGE Publications.

- Weissberg-Benchell, J., & Antisdel-Lomaglio, J. (2011). Diabetes-specific emotional distress among adolescents: Feasibility, reliability, and validity of the Problem Areas in Diabetes-Teen version. *Pediatric Diabetes*, *12*(4 Pt 1), 341-344. doi:10.1111/j.1399-5448.2010.00720.x
- Weissberg-Benchell, J., Wolpert, H., & Anderson, B. (2007). Transitioning from pediatric to adult care: A new approach to the post-adolescent young person with type 1 diabetes. *Diabetes Care, 30*(10), 2441-2446.
- Welch, G., Jacobson, A. M., & Polonsky, W. H. (1997). The Problem Areas in Diabetes Scale.
 An evaluation of its clinical utility. *Diabetes Care*, 20(5), 760.
 doi:10.2337/diacare.20.5.760
- Welch, G., Weinger, K., Anderson, B., & Polonsky, W. H. (2003). Responsiveness of the Problem Areas in Diabetes (PAID) questionnaire. *Diabetic Medicine*, 20(1), 69-72. doi:10.1046/j.1464-5491.2003.00832.x
- Wentzell, K., Vessey, J. A., Laffel, L., & Ludlow, L. (2020). Diabetes distress in emerging adults: Refining the Problem Areas in Diabetes--Emerging Adult version using Rasch analysis. *Journal of Applied Measurement*, 21(4), 481-495.
- Wentzell, K., Vessey, J. A., & Laffel, L. M. B. (2020). How do the challenges of emerging adulthood inform our understanding of diabetes distress? An integrative review. *Current Diabetes Reports*, 20(6), 21. doi:10.1007/s11892-020-01301-3
- Wentzell, K., Walker, H., Hughes, A., & Vessey, J. A. (2021). Engaging social media influencers to recruit hard to reach populations: A method and technique. Manuscript in preparation.

Willis, G. B. (2004). Cognitive interviewing. Thousand Oaks, CA: SAGE

- Willis, G. D., Grace, J. P., & Roy, J. C. (2008). A central unifying focus for the discipline:
 Facilitating humanization, meaning, choice, quality of life, and healing in living and dying. *Advances in Nursing Science*, *31*(1), E28-E40.
 doi:10.1097/01.ANS.0000311534.04059.d9
- Wright, B. D., & Masters, G. N. (1982). Rating scale analysis. Chicago, IL: MESA Press.
- Wright, B. D., & Stone, M. H. (1979). Best test design. Chicago, IL: MESA Press.
- Wright, B. D., & Stone, M. H. (1999). *Measurement essentials* (2nd ed.). Wilmington, DE: Wide Range.
- Zagarins, S., Allen, N., Garb, J., & Welch, G. (2012). Improvement in glycemic control following a diabetes education intervention is associated with change in diabetes distress but not change in depressive symptoms. *Journal of Behavioral Medicine*, 35(3), 299-304. doi:10.1007/s10865-011-9359-z
- Zoffmann, V., Vistisen, D., & Due-Christensen, M. (2015). Flexible guided self-determination intervention for younger adults with poorly controlled type 1 diabetes, decreased HbA1c and psychosocial distress in women but not in men: A real-life RCT. *Diabetic Medicine*, 32(9), 1239-1246. doi:10.1111/dme.12698

Running Head: DIABETES DISTRESS IN EMERGING ADULTHOOD

Appendix A

PAID-EA 25-item measure

As a young adult, living with diabetes can be difficult. Listed below are emotions, worries and feelings that some young adults with diabetes may experience.

Please think about your recent emotions and the burden of living with diabetes <u>now and during the past</u> week.

Please choose one answer that best describes how much you disagree or agree with each statement.

	Disagree (0)	Somewhat Disagree (1)	Neutral (2)	Somewhat Agree (3)	Agree (4)
I feel that diabetes is taking up too much of my mental energy every day. (1)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I feel annoyed when people say something ignorant about having diabetes. (2)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I am tired of having to explain diabetes to others. (3)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I have other things in my life that keep me from managing my diabetes. (4)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I feel judged by others because I have diabetes. (5)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I worry about being able to socialize because of how alcohol affects my blood sugar. (6)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I worry that a new romantic partner will see my diabetes devices or supplies. (7)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I worry about having kids in the future because of my diabetes. (8)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I worry that my blood sugar will go low or high during sex. (9)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I worry that diabetes will get in the way of what I want to do with my life. (10)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I feel that I must be perfect in my diabetes management. (11)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
l feel alone with diabetes. (12)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I avoid doing diabetes management tasks when other people are around. (13)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc

I feel like a failure when I have a high A1c. (14)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I feel overwhelmed about having to do diabetes all by myself. (15)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I worry about living alone because I have diabetes. (16)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I don't want to know my blood sugar when it is high. (17)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I feel frustrated about interruptions from diabetes (during sleep, work, school). (18)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I worry about diabetes complications. (19)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I don't know how to make diabetes a priority when I have a lot of changes in my life. (20)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I worry about the cost of diabetes. (21)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I worry about having a low blood sugar. (22)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I am too tired of having diabetes to take care of it. (23)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I feel like I cannot take as many risks as my friends. (24)	0	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I feel like I am trying my hardest to take care of diabetes, but it never works. (25)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc

Tentative metric to score the PAID-EA:

Sum responses for all items for a range of 0 to 100. Higher score indicates more diabetes distress.

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