

**TRANSITIONING TO COLLEGE  
WITH TYPE 1 DIABETES MELLITUS:  
THE PARENTAL PERSPECTIVE**

by

Michelle M. Ness

A dissertation submitted to the Faculty of the University of Delaware in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing Science

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Approved:

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Kathleen Schell, Ph.D., R.N.  
Interim Senior Associate Dean of Nursing

Approved:

---

Kathleen S. Matt, Ph.D.  
Dean of the College of Health Sciences

Approved:

---

Douglas J. Doren, Ph.D.  
Interim Vice Provost for Graduate and Professional Education and  
Dean of the Graduate College

I certify that I have read this dissertation and that in my opinion it meets the academic and professional standard required by the University as a dissertation for the degree of Doctor of Philosophy.

Signed:

---

Jennifer L. Saylor, Ph.D., APRN, ACNS-BC  
Professor in charge of dissertation

I certify that I have read this dissertation and that in my opinion it meets the academic and professional standard required by the University as a dissertation for the degree of Doctor of Philosophy.

Signed:

---

Janice Selekman, D.N.Sc., R.N., NCSN, FNASN  
Member of dissertation committee

I certify that I have read this dissertation and that in my opinion it meets the academic and professional standard required by the University as a dissertation for the degree of Doctor of Philosophy.

Signed:

---

Barbara Habermann, Ph.D., R.N., FAAN  
Member of dissertation committee

I certify that I have read this dissertation and that in my opinion it meets the academic and professional standard required by the University as a dissertation for the degree of Doctor of Philosophy.

Signed:

---

Xiaopeng Ji, Ph.D., M.S.N., M.A., R.N.  
Member of dissertation committee

I certify that I have read this dissertation and that in my opinion it meets the academic and professional standard required by the University as a dissertation for the degree of Doctor of Philosophy.

Signed:

---

Ann Bell, Ph.D.

Member of dissertation committee

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## ABSTRACT

Over 2 million families will begin the transition to college in fall 2020. The transition to college is an exciting and challenging time for families. As emerging young adults (EYA) are completing high school and preparing to begin their college career, parents are simultaneously undergoing their own transition from being the parent of an adolescent to becoming the parent of an EYA. While this is a normative life transition, parents who are not able to adapt to individual and systemic changes during the transition period are at risk of entrenchment, subverting their healthy development along the lifespan. This transition is even more complicated when coupled with type 1 diabetes mellitus (T1DM).

Type 1 diabetes mellitus is expected to impact nearly 600,000 youth by the year 2050. As EYAs with T1DM prepare to leave for college, parents must relinquish responsibility for T1DM management. Parents may be unwilling to relinquish control of T1DM management in the college setting due to fear of the unknown as well as increased risk for EYA involvement in high risk behaviors such as alcohol and drug use. Parents who are confident in their EYA's ability to manage T1DM at college may be more comfortable with their EYA's departure, but concerns remain. The aim of this dissertation study was to explore the experience of parents of EYAs with T1DM before, during, and after the transition to college and address gaps in the literature to inform recommendations for future research and clinical interventions.

Study one (chapter 2) systematically reviewed existing literature focused on the barriers and facilitators experienced by parents as they transitioned their EYA with T1DM to college. The review of the literature identified three potential barriers:

developing and promoting autonomy, evolving relationships and roles in the parent/youth dyad, and distress. Study two (chapter 3) sought to explore the experience of mothers of EYAs with T1DM before the college transition. Four themes emerged: concern for health and safety at college; evolving roles of the parent and emerging adult dyad; communication dynamics; and social support systems. Study three (chapter 4) further explored the parental experience after the transition to college by identifying barriers and facilitators experienced by parents as their EYA with T1DM completed the transition to college. Several facilitators and barriers were identified, including EYAs' ability to self-manage; the EYA's new social support network including friends and roommates; and levels of support for parents.

Findings from this dissertation indicate that parents of EYAs with T1DM have higher levels of concern and experience barriers during the transition to college. Parents of EYAs with T1DM require additional levels of support and education from diabetes care providers as well as colleges and universities during the college transition process. Further research is needed to determine the nature of this support and to develop family centered interventions to assist parents to transition their EYA with T1DM to college.

## Chapter 1

### **INTRODUCTION TO THE PROBLEM**

Transition is defined as the “passage from one state, stage, subject, or place to another” (Merriam Webster, 2018) and is typically triggered by life events and/or changes in individuals or their environments. During a transition period, which may occur at any stage of life, individuals undergo significant psychosocial and sometimes physical changes, going from a stable state through a period of instability, then returning to a new stable state (Meleis, 2010). For parents, one such developmental and situational transition occurs as children approach emerging adulthood, defined as the period of time from ages 18-25 (Arnett, 2000). This is typically the time when emerging young adults (EYA) advance their education beyond high school and/or begin their employment, move out of their familial home, and begin their own families, heralding the beginning of a critical period as they work to gain independence from parents and become more responsible for their life course (Napolitano et al., 2017). Concurrently, parents are transitioning from their role as the parent of an adolescent to their new role as the parent of an EYA. During this time, parents must simultaneously support their EYA’s transition to adulthood and redefine their own roles and relationships within the family.

#### **Transition and Families**

This family transition is a time of great change for families as the EYA strives for independence and shifts their role within the family. At the same time, parents are

adapting to other normative life events, including career changes, the need to be productive, and the departure of children from home (American Psychological Association [APA], 2014). Each stage requires a major change in how the family is organized and how it functions. Moving from one stage to another requires individuals and families to renegotiate their relationships with each other as they respond to individual and systemic changes, including various entries and exits from the family system (McGoldrick, Preto, & Carter, 2015). Families who are not able to adapt to both the individual and systemic changes affecting family members will become stuck or entrenched, subverting their healthy development along the lifespan (McGoldrick, et al., 2015).

### **The Transition to College**

In fall 2020, over 2 million students will be transitioning to college (National Center for Educational Statistics, 2019). As EYAs transition to college, parents are beginning to redefine the parent-child relationships to accommodate the child moving in and out of the family system (McGoldrick et al., 2015). The transition from parent of an adolescent to becoming the parent of an EYA happens at a time when EYAs are preparing for the future and may decide to attend college. When parents are preparing to send their EYA to college, the final years of high school can be fraught with stress related to the college-application process and the realization that the EYA will soon be leaving the familial home. Parents may be focused on the logistics of ensuring a smooth college transition for themselves and their EYA, rather than the emotional ramifications of the impending departure of their child (Karp, Holmstrom, & Gray, 2004). Despite actively seeking independence, EYAs are increasingly reliant on parents for help while they pursue their educational and employment goals without the

need to support themselves (Sandberg-Thoma, Snyder, & Jang, 2015). Parents, in turn, are willing to provide support, as they perceive it will promote success as their EYA progresses towards adulthood, leading to a state of quasi-independence (Settersten & Ray, 2010).

This transition is a normal part of life for many families of EYAs; however, a lack of coping resources can cause families to become disorganized and incapable of successfully transitioning to the next stage (McGoldrick et al., 2015). Families who are not able to manage the transition appropriately may experience increased stress as a result of unmanaged tensions and anxieties, leading to entrenchment and failure to successfully move to the next stage of life (McGoldrick et al., 2015).

### **Preparation for the Transition to College with Type 1 Diabetes Mellitus**

The transition to adulthood remains a critical period, especially when coupled with the presence of a chronic condition (Livesey & Rostain, 2017). This is particularly true for EYAs with type 1 diabetes mellitus (T1DM). Affecting approximately 193,000 youth under the age of 20 in the United States, T1DM is expected to impact nearly 600,000 youth by the year 2050 (American Diabetes Association [ADA], 2019; Centers for Disease Control and Prevention [CDC], 2017). Complications from T1DM include amputations, cardiovascular disease, nephropathy, neuropathy, and retinopathy; diabetes and its complications are the seventh leading cause of death in the United States (ADA, 2019). While proper T1DM management in adolescence can prevent these complications, attaining and maintaining optimal glucose control (defined as a hemoglobin A1c goal of <7.5% [58 mmol/mol] in pediatric age-groups; ADA, 2019) requires support from parents as well as increasing responsibility for self-management by the adolescent.

Diabetes management, a process that may be increasingly complicated for both the teen and parent, can be challenging for families as they prepare for and eventually transition to college. Research indicates that parents must turn over primary responsibility for diabetes care to emerging adults through a series of planned interventions undertaken with the diabetes care team (Palladino et al., 2013; Smart, Annan, Bruno, Higgins, & Acerini, 2014). This may require a renegotiation of diabetes-related responsibilities when the EYA returns home from college during semester breaks and holidays. Continued parental support is paramount in attaining and maintaining optimal glucose control; however, the EYA must take increasing responsibility for self-management (Agarwal et al., 2016; Lotstein et al., 2013; Majumder, Cogen & Monaghan, 2017). The need to transition self-management tasks becomes particularly acute as the EYA is preparing to transition to college. These changes may create a challenging family dynamic for parents who are balancing the changing needs of their child and the demands of their own transition. This complexity is greater for parents who have a child with a chronic condition such as T1DM.

### **After the Transition to College with T1DM**

While the diabetes health care team provides developmentally appropriate interventions and support for the family ultimately leading to independence in self-management for EYAs, the transition to college remains challenging for both EYAs and families alike and is a period of great vulnerability (Agarwal et al., 2016; Lotstein et al., 2013; Majumder et al., 2017). Some college students with T1DM struggle with independently navigating the many facets of college life that may impact T1DM management, including academics, sleep, nutrition, and physical activity as well as the threat of risky behaviors and mental health issues (Palladino et al., 2013; Saylor &

Calamaro, 2016; Smart et al., 2014). Involvement in high risk activities such as alcohol use, smoking, and drug abuse lead to poor glycemic control placing youth at risk for immediate and long-term diabetes complications (Balfe, 2007; Helgeson et al., 2014; Monaghan, Helgeson, & Wiebe, 2015).

### **Background and Significance**

This section provides theoretical and operational definitions of key concepts, including transition, facilitators and barriers. In addition, known challenges in the transition to college with T1DM are presented. This background information provides the necessary foundational knowledge to aid in understanding the research questions.

### **Theoretical and Operational Definitions**

Transition.

Transitions are typically triggered by life events and/or changes in individuals or their environments (Meleis, 2010). Transitions may be classified as developmental, situational, health-illness, and/or organizational (Meleis, 2010). The transition from the parent of a dependent adolescent to parent of an EYA may be considered both developmental and situational (Meleis, 2010) and takes place concurrently with the EYA's transition from adolescence to adulthood. As EYAs strive for independence and shift their role within the family, parents are adapting to normative life events, including career changes, the need to be productive, and the departure of children from the home (APA, 2014).

## Barriers.

Barriers may be viewed as actions, individuals, or processes, that prevent individuals from reaching a desired outcome. Barriers in self- and family management of chronic conditions can be broken down into child-specific variables and family-specific variables. Child-specific barriers include lack of knowledge about the disease process, psychological distress, limited motivation for self-care, and overall level of self-management experience (Grey, Schulman-Green, Knafl, & Reynolds, 2015). Family specific barriers include variables such as education level of the parent, and family structure, as well as limited resources or lack of access to healthcare providers (Schulman-Green, Jaser, Park, & Whittlemore, 2016; Zhang, Wei, Shen, & Zhang, 2015). In the transfer of responsibility for management of chronic conditions from parent to EYA, barriers include role ambiguity for both parent and EYA as well as that of the healthcare provider (Nightingale, McHugh, Kirk, & Swallow, 2019). For the purposes of this study, barriers to the transition process will be viewed as those actions or processes that make the transition to college with T1DM more difficult for parents and EYAs.

## Facilitators.

Facilitators may be viewed as actions, individuals, or processes that help bring about a desired outcome, such as learning, productivity, or communication. Facilitators in self-management may be broken down into those that are child specific or family specific. Child specific facilitators include increased self-efficacy for self-management and high levels of motivation to take over responsibility for care (Grey et al., 2015). Family specific facilitators include the family's social network and their available financial resources (Schulman-Green et al., 2016). As the responsibility for

self-management of a chronic condition transfers from parent to EYA, research has demonstrated that EYAs who are directly involved in the decision-making process are better prepared to take control (Jordan, Wood, Edwards, Shepherd, & Joseph-Williams, 2018). For the purposes of this study, facilitators to the transition process will be viewed as those actions or processes that facilitate the transition to college with T1DM for parents and EYAs.

### **Known Challenges During the Transition Process**

While it is understood that T1DM management is facilitated and positively influenced by parental support as well as mutual respect between the parent and the EYA (Carcone, Ellis & Naar-King, 2012; Hanna, Dashiff, Stump, & Weaver, 2013; Lokes, Gingras, Philippe, Koestner, & Fang, 2010; Moreira & Canavarro, 2016; Schultz & Smaldone, 2017), evolving roles in the parent/EYA dyad and increased levels of distress related to the transition may lead parents to struggle with relinquishing control of diabetes care to their child (Ness, Saylor, & Selekman, 2018). Parents of college-bound EYAs with T1DM have additional concerns due to the health-related, behavioral and developmental changes that occur for EYAs during high school and the subsequent transition to college. The transition may lead to increased worry and distress for parents, as going away to college often puts EYAs at increased risk for poor glycemic control, loss to follow-up care, acute complications, psychosocial issues, and sexual and reproductive health issues (ADA, 2019).

Challenges faced by parents.

Parents may be concerned about their EYA's potential involvement in high risk activities, such as alcohol use, smoking, and drug abuse that may lead to poor

glycemic control placing them at risk for immediate and long-term diabetes complications (Balfe, 2007; Helgeson et al., 2014; Monaghan et al., 2015). This increased level of concern may cause parents to have difficulty letting go and become stagnant in their own transition. Parents caring for children with T1DM report high levels of stress related to diabetes management, especially in attaining and maintaining optimal glucose control and transitioning their children to self-management as they mature (Carcone et al., 2012; Hanna, Weaver, Stump, Guthrie, & Oruche, 2013). Parents report pressure from healthcare providers to take responsibility for diabetes care tasks, despite the fact that EYAs should be managing their own care; this contradiction in messages creates a barrier to the attainment of autonomy (Sullivan-Bolyai et al., 2014). Parents of EYAs with T1DM are integral to a successful transition but may inadvertently delay or hamper the process due to fear or worry as well as other factors, such as access to support and confidence in their young adult's ability to manage their condition (Hessler, Fisher, Polonsky, & Johnson, 2016; Ness et al., 2018; Schultz & Smaldone, 2017).

Challenges faced by emerging young adults.

EYAs, who should be primarily responsible for their T1DM self-management, may continue to remain dependent on parents for their diabetes care (Hessler et al., 2016; Ness et al., 2018; Sullivan-Bolyai et al., 2014). This may lead to role confusion, where the T1DM management responsibilities of the parent and those of the EYA are not clearly delineated. EYAs with T1DM describe that taking over responsibility for self-management is burdensome, leading them to feel that they are constantly being watched. EYAs indicate a feeling of inadequacy, particularly related to a perceived knowledge deficit, potentially leading to feelings of anxiety, depression, poor self-

esteem, problems with coping, and struggles with peer and parental relationships (Babler & Strickland, 2015; Strand, Broström, & Haugstvedt, 2018). Parents may struggle with relinquishing control, fearing that their EYA is not responsible enough to manage their T1DM as well as fearing the unknown as their EYA transitions to life on a college campus (Carcone et al., 2012; Hanna, Weaver, et al., 2013; Schultz & Smaldone, 2017).

### **Gaps in the Literature**

Current research findings are ambiguous regarding the needs of parents as they transition their EYAs with T1DM to college. Within the realm of nursing, literature about transition and diabetes management focuses on transitioning from pediatric to adult care providers and practice-based interventions to improve the healthcare transition process that may ultimately improve glycemic control for EYAs. There is a significant gap in the current research focusing on parents of EYAs with T1DM and even less focusing on the parental perspective of the transition to college with T1DM.

While research has shown that parental support for EYAs transitioning with T1DM is an integral part of the transition process (Babler & Strickland, 2015; Hessler et al., 2016; Strand et al., 2018), there is a paucity of literature regarding the level of support EYAs need from parents during the college transition. Additionally, there is a dearth in the literature regarding the types of support that parents need to manage their own transition as they assist their college-bound EYA with T1DM during this time. This is significant; parents who are able to manage their own transition during their EYA's transition to college with T1DM may have decreased levels of stress. This, in turn, may lead them to be able to provide better support and guidance during the

transition to self-care for their emerging adults (Akre & Suris, 2014; Mendonça & Fontaine, 2014).

To fill the gaps in the literature, this dissertation study addressed the following questions:

1. What literature exists regarding the potential barriers that impact parents as they transition their college-bound EYA with T1DM to college?
2. What are the experiences of parents of EYAs with T1DM as they prepare for their high school senior's transition to college?
3. What were the barriers and facilitators experienced by parents of EYAs with T1DM as their college freshman or sophomore moved along the continuum of the transition to college?

## **Conceptual Framework**

### **Family Life Cycle Theory**

Family life cycle theory focuses on the development of the family, with specific attention paid to the role of the parent (McGoldrick et al., 2015). Viewing the family within the larger social context, the family life cycle is comprised of six different stages: 1) leaving home; 2) joining families through marriage; 3) families with young children; 4) families with adolescents; 5) launching children and moving on; and 6) families in later life (McGoldrick et al., 2015; see Table 1).

In addition to defining the stages of family development, family life cycle views the reciprocal flow of stressors in a family as both vertical and horizontal (McGoldrick et al., 2015). The vertical axis encompasses issues past and present that may affect family members, such as temperament, genetics, and disabilities. The horizontal axis relates to the individual's development (emotional, cognitive,

interpersonal, and physical) over the course of the life span within a specific context. The transition from parenting in the adolescent stage to the launching of an emerging adult stage is considered a horizontal stressor. When viewed in this sense, transition involves changing relationship patterns to accommodate the entry, exit, and development of the EYA in a way that promotes the developmental needs of both the parent and the child (McGoldrick et al., 2015).

Table 1 The Family Life Cycle

Phases of the family life cycle		
<i>Family Life Cycle Stage</i>	<i>Emotional Process of Transition: Key Principles</i>	<i>Second Order Changes in Family Status Required to Proceed Developmentally</i>
Leaving home: Single young adults	Accepting emotional and financial responsibility for self	Differentiation of self in relation to family of origin. Development of intimate peer relationships. Establishment of self in respect to work and financial independence.
The joining of families through marriage: The new couple	Commitment to new system	Formation of marital system. Realignment of relationships with extended families and friends to include spouse.
Families with young children	Accepting new members into the system	Adjusting marital system to make space for children. Joining in child rearing, financial and household tasks. Realignment of relationships with extended family to include parenting and grandparenting roles.
Families with adolescents	Increasing flexibility of family boundaries to permit children's independence and grandparents' frailties	Shifting of parent/child relationships to permit adolescent to move into and out of system. Refocus on midlife marital and career issues. Beginning shift toward caring for older generation.

Table 1 continued.

<p>Launching children and moving on at midlife</p>	<p>Accepting a multitude of exits from and entries into the family system</p>	<p>Renegotiation of marital system as a dyad. Development of adult-to-adult relationships between grown children and their parents. Realignment of relationships to include in-laws and grandchildren. Dealing with disabilities and death of parents (grandparents).</p>
<p>Families in later life</p>	<p>Accepting the shifting generational roles</p>	<p>Maintaining own and/or couple functioning and interests in face of physiological decline: exploration of new familial and social role options. Support for more central role of middle generation. Making room in the system for the wisdom and experience of the elderly, supporting the older generation without overfunctioning for them. Dealing with loss of spouse, siblings, and other peers and preparation for death.</p>

*Note.* Adapted from McGoldrick, M., Preto, N., & Carter, B. (2015). Overview. In M. McGoldrick, N. Preto, & B. Carter (Eds.) *The expanding family life cycle: Individual, family, and societal perspectives* (5th Ed.). Upper Saddle River, NJ: Pearson.

McGoldrick and colleagues (2015) note that stress is at its highest during transition periods and developmental tasks that are not resolved at that particular time will continue to hinder future transactions and relationships. This level of stress may be enhanced during the college transition with T1DM. As EYAs move towards independence, they must increase their capacity for diabetes management. Research has shown that parents who are able to manage their own transition during this time are better able to support EYAs as they take over management of their diabetes care (Akre & Suris, 2014; Monaghan et al., 2015; Ness et al., 2018). While EYAs may be more likely to succeed in T1DM management if they learn how to manage their care with the continued support of their parents, concerns about the EYA's self-efficacy remain (Castensøe-Seidenfaden et al., 2017; Ersig, Tsalikian, Coffey, & Williams, 2016; Law, Walsh, Queralt, & Nouwen, 2013) Parents who are concerned about their

EYA's ability to manage their diabetes while at college experienced increased levels of distress, which may negatively impact the transition process (Castensøe-Seidenfaden et al., 2017; Hessler et al., 2016; Law et al., 2013). Families who are not prepared for the stress of transition may fail to meet the developmental needs of one or more family members leading to entrenchment and an imbalance in the family life cycle.

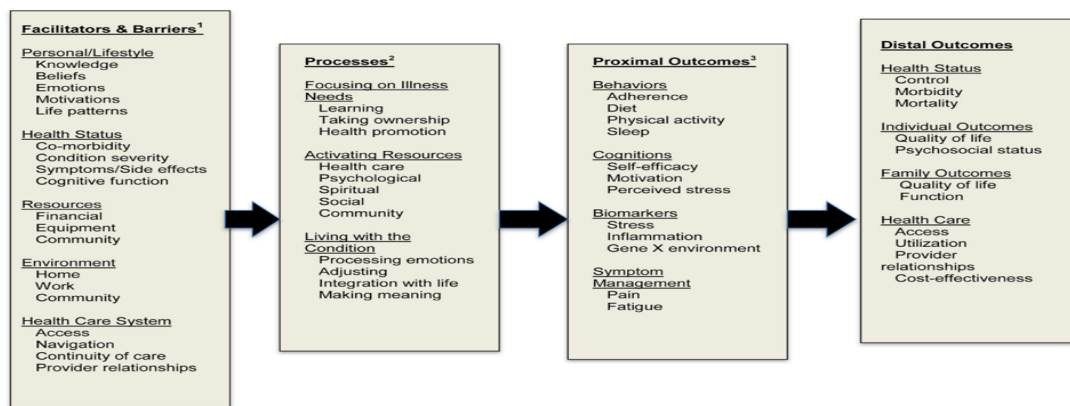
### **Revised Self- and Family Management Framework**

The transition to college is a unique stressor in the “launching children and moving on stage” of the family life cycle. This stage is complicated further by the presence of a chronic condition such as T1DM. Parents have unique needs during college transition of their child with T1DM. Parents must promote autonomy while supporting their own and their EYA's needs during this time; however, recent research indicates that there are several barriers to the transition process. The Revised Self and Family Management Framework, developed by Grey, Schulman-Green, Knafl, and Reynolds (2015), builds upon previous work by Grey and colleagues in 2006. The original Self- and Family Management Framework (Grey, Knafl, & McCorkle, 2006) was developed to guide research to advance self- and family management science by highlighting relationships among risk and protective factors, self- and family management processes and health outcomes. The Revised Self- and Family Management Framework (Grey et al., 2015) builds upon previous work by focusing on the complex nature of self-management science, including the need to address the processes associated with both self- and family management by gaining a better understanding of what facilitates positive outcomes as well as the infrastructure and

integrated systems of care that inform sustainable self- and family management interventions.

This framework identifies facilitators and barriers that may influence self-and family management processes, noting both proximal and distal outcomes (Grey et al., 2015; Figure 1). Facilitators and barriers include personal/lifestyle, health status, resources, environmental, and health care system factors that may be associated with the self-management of chronic conditions (Grey et al., 2015). Proximal outcomes can be viewed as mediators of self-and family management (Grey et al., 2015). These may include cognitions (self-efficacy, fear, perceived stress) that result from self- and family management that ultimately lead to distal outcomes; these outcomes include individual outcomes such as greater glycemic control for EYAs and increased quality of life for both parents and EYAs. Distal outcomes such as disease control and quality of life, are increasingly important. Family outcomes, especially functioning, are essential in determining the impact of self- and family management.

Figure 1 A Revised Self-and Family Management Framework



*Note.* Reprinted from Nursing Outlook, 63(2), Grey, M., Schulman-Green, D., Knaf, K., & Reynolds, N. R., A revised self- and family management framework, 162-170. Copyright (2015), with permission from Elsevier.

This body of work employs the Revised Self-and Family Management Framework by focusing on the identification of facilitators and barriers to gain a better understanding of how parents navigate their EYA's transition to college with T1DM with the ultimate goal of informing family-centered interventions to support parents and EYAs during the process.

Parents may be viewed as both a barrier and a facilitator to the transition process. Research has shown that parents who are able to manage their own transition during this time are better able to support EYAs as they take over management of their diabetes care (Akre & Suris, 2014; Monaghan et al., 2015; Ness et al., 2018). Viewing the parental transition through the lens of The Revised Self and Family Management Framework (Grey et al., 2015) will allow the researcher to examine the personal and environmental facilitators and barriers that impact the transition to college for parents and EYAs with T1DM.

### **Purpose and Specific Aims**

The purpose of this dissertation is to explore the experience of parents before, during, and after their EYA with T1DM transitions to college. Serving to address existing gaps in the literature and to inform recommendations for future research about the parental experience during their EYAs transition to college with T1DM, the specific aims of this dissertation were the following:

Aim 1.

Using PRISMA guidelines, systematically review the literature to identify the state of the science about facilitators and/or barriers impacting parents as they transition their EYA with T1DM to college (Chapter 2).

Aim 2.

Explore the experience of parents of high school students with T1DM as they prepared for the college transition (Chapter 3).

Aim 3.

Identify barriers and facilitators faced by parents as their EYA with T1DM completed their freshman or sophomore year of college (Chapter 4).

### **Significance**

This research is the first to focus specifically on the experience of parents of EYAs with T1DM during the transition to college. Gaining the parent perspective of the college transition will provide insight into the needs of parents and families during this time. Research has shown that focusing on knowledge and behaviors alone may not improve outcomes in chronic conditions. Identifying the challenges faced by parents of EYAs during the college transition process will inform the development of interventions designed to support families as they move to the next stage of life with T1DM. This research can be used by T1DM healthcare providers and campus professionals to support family-centered care by focusing on the needs of both parents and EYAs. Supporting the needs of parents of EYAs with T1DM during this time may serve to reduce diabetes-related complications for EYAs and increase overall quality of life for both members of the dyad.

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## Chapter 2

### **BARRIERS AND FACILITATORS INFLUENCING PARENTAL TRANSITION OF COLLEGE-BOUND YOUTH WITH TYPE 1 DIABETES MELLITUS: AN INTEGRATIVE REVIEW**

The information in this chapter is adapted, with permission from Springer Science & Business Media (Appendix A), from Barriers and facilitators influencing parental transition of college-bound youth with type 1 diabetes mellitus: An integrative review by M. M. Ness, J. L. Saylor, and J.A. Selekman, published in Current Diabetes Reports (Volume 44, Issue 2, pages 178-187, April 2019). M. Ness was responsible for the conception and design of the study; the acquisition and analysis of data; drafting and revising the manuscript; and approval of the version of the manuscript to be published. J. Saylor was responsible for the analysis of data; revising the manuscript; and approval of the version of the manuscript to be published. J. Selekman was responsible for revising the manuscript; and approval of the version of the manuscript to be published.

Current Diabetes Reports publishes reviews on subjects pertinent to all aspects of diabetes epidemiology, pathophysiology, and management. Contributions from leading experts are solicited in each relevant domain that will be of interest to clinicians, scientists, and translational investigators.

## **Abstract**

The purpose of this review was to synthesize current research about potential barriers impacting parents as they transition their college-bound youth with type 1 diabetes mellitus (T1DM) to college. Seven studies, five qualitative and two quantitative, met the qualifications for inclusion in this study by focusing on parents and were included in this review. Three potential barriers impacting the parental experience during the transition of their youth with T1DM to college were identified: developing and promoting autonomy, evolving relationships and roles in the parent/youth dyad, and distress. Parents consistently indicated concern about their youth's ability to self-manage their T1DM and lack of support for their own transition. This review indicates that several barriers may influence parents of adolescents with T1DM as they transition to becoming the parent of a college-bound youth with T1DM. The parental transition of launching their youth to college is more complex and unique for parents of youth with T1DM than for parents of youth without chronic conditions. Additional research focusing on the identification of desired supports for parents and the development of specific interventions to assist parents as they transition with their college-bound youth with T1DM is recommended.

## **Introduction**

The transition from adolescence to adulthood and the concurrent transition from high school to college heralds a time of great change for parents and their children. As youth[1] (defined by the United Nations as persons between the ages of 15 and 24 years) strive for independence and shift their role within the family, parents are adapting to other normative life events including career changes, the need to be productive, and the departure of children from the home.[2] This transition involves changing relationship patterns to accommodate the movement of the youth in and out of the family system as well as promoting the developmental needs of both the parent and the child.[3] McGoldrick and colleagues (2016) note that stress is at its highest during transition periods, and developmental tasks that are not resolved at that particular time will continue to hinder future transactions and relationships. Families who are not prepared for the stress of transition may fail to meet the developmental needs of one or more family members leading to entrenchment and an imbalance in the family life cycle.[3]

For parents, the beginning of their children's transition from adolescence to adulthood coincides with the youth's final years of high school. Youth may decide to join the workforce directly from high school or choose to attend college. For those who choose to attend college, this may be a time of increased excitement and stress related to the college-application process. This time can be particularly stressful for families of youth who decide to live on campus as parents must cope with the realization that their youth will soon be leaving the familial home. During this time, parents may be focused on the logistics of ensuring that the transition to college is

smooth for themselves and their youth, rather than the emotional ramifications of the impending departure of their child.[4,5]

Parents may mourn the loss of their role as a parent leading to difficulties letting go as they begin to realize they are no longer needed by their youth.[6] This transition is a normal part of life for families in the US; however, a lack of coping resources can cause families to become disorganized and incapable of successfully transitioning to the next stage, resulting in unmanaged tensions and anxieties. This may lead to stress-related health problems in parents, including heart disease, high blood pressure, diabetes, and an increased risk for depression or anxiety, as well as a failure to successfully move to the next stage of family life.[3,7]

The transition to college may be more challenging for parents of youth with a chronic condition such as type 1 diabetes mellitus (T1DM) than parents of youth without chronic conditions. Ideally, parents will turn over primary responsibility for T1DM management to youth through a series of planned interventions undertaken with the T1DM healthcare team, prior to the youths' departure from home.[8–12] Transitioning to college often increases youths' risk for poor glycemic control, loss to follow-up care, acute complications, psychosocial issues, and sexual and reproductive health issues leading to increased worry and distress for parents at a time when communication about T1DM management decreases.[13,14]

College students with T1DM may struggle with independently navigating the many facets of college life that may impact T1DM management, including academics and changes in sleep, nutrition, and physical activity patterns as well as the threats of risky behaviors and mental health issues.[8,15,16] Parents may be concerned about their youth's potential involvement in high risk activities such as alcohol use,

smoking, and drug abuse that may lead to poor glycemic control placing them at risk for immediate and long-term T1DM complications.[17–19] Increased parental worry, fear of the unknown, and concerns about the youth’s self-efficacy may complicate a parent’s ability to successfully prepare themselves to transition from parent of an adolescent to launching an adult causing parents to become stagnant in their own transition, inadvertently stagnating their youth’s transition as well.[19–22]

Youth with T1DM, rather than parents, remains the focus in most of the chronic condition transition literature. There is a breadth of T1DM literature focused on the youth transition from pediatric to adult health care; however, very little literature focuses on the college transition of youth with T1DM, and even fewer studies focus on the parental perspective during this time. While parents play a significant role in the transition process for youth with T1DM as they move from high school to college, parents’ needs are not fully understood. Therefore, the purpose of this review is to identify the state of the science regarding potential barriers that influence parents as they help their youth with T1DM transition to college and living independent of parents for the first time. Gaps in the literature will be identified to inform recommendations for clinical practice and future research.

## **Methods**

An integrated review of the literature was conducted using Whittemore and Knafl’s updated methodology for integrative reviews (2005).[23] A comprehensive search strategy was developed to identify relevant studies through computer-assisted database searches of Web of Science, Scopus, PubMed, and CINAHL. Search terms included ‘parent’, ‘transition’, and ‘diabetes’. Studies were included if they were (a) qualitative or quantitative research on parents of youth/emerging young adults (ages

14-25) with T1DM and (b) published in an English-language journal between 2013 and the present. One author read the titles and abstracts of each article and excluded those that (a) were not focused on parent outcomes, (b) focused on type 2 diabetes or other chronic conditions, (c) focused on providers or healthcare transition, (d) focused exclusively on interventions for the youth, and/or (e) focused exclusively on youth/emerging young adult outcomes.

All included articles were read and analyzed by both authors and systematically summarized. Studies were evaluated for eligibility and quality was appraised using established tools.[24,25] Data were analyzed using content analysis and were displayed in chart format to aid in the identification of patterns or similarities in the data.[26] Key concepts were grouped into categories and became the basis for overarching themes. From these overarching themes, conclusions were drawn and were informed by primary studies, ensuring that interpretations were grounded in the data. PRISMA (Preferred Reporting for Systematic Reviews and Meta-Analyses) guidelines were followed.[27]

## **Results**

The final sample consisted of five qualitative articles and two quantitative articles (Table 1). All five qualitative studies used a descriptive methodology and were of good quality. Researchers used individual interviews (n=4) and focus groups (n=1). One study used a dyadic approach. Three studies analyzed data via thematic analysis while one study used content analysis. Two studies were guided by a framework while another used visual storytelling in conjunction with interviews. Both quantitative studies were cross-sectional. One study focused on the transition from pediatric to adult healthcare providers (HCPs), while only one study[21] focused exclusively on

the experience of parents during the transition to college. The remaining studies focused on transition to adulthood.

Table 2 Description of studies reviewed

Study (Country)	Sample	Purpose	Design	Results
Castensøe-Seidenfaden et al. (2017). (Denmark) [28]	<i>N</i> =13 caregiver/ adolescent dyads: mean age of adolescent 17.	To explore and describe the experiences of adolescents and their parents living with type 1 diabetes, to identify their needs for support to improve adolescents' self-management skills in the transition from child- to adulthood.	Qualitative, explorative. (Visual storytelling).	Parents are fundamental in supporting the adolescents' self-management-work; however, the parties have unspoken concerns and challenges
Walsh et al. (2018). (Ireland) [31]	<i>N</i> =20 parents/ providers/ "young adults": mean age of young adult not indicated.	This study aims to describe the perceptions of young adults, parents of young adults, and healthcare professionals of the transition process for young adults with T1DM in the West of Ireland.	Qualitative, thematic (Interviews).	This study highlights the importance of encouraging adolescents' autonomy in the years leading to transition. Being flexible and supportive of both parents and adolescents including the provision of mental health services are other important considerations.
Law et al. (2013) (United Kingdom) [32]	<i>N</i> =203 primary caregiver and adolescent: mean age of adolescent 14.5.	To examine the association of adolescent and parent diabetes distress with perceived consequences, dietary self-efficacy, and discrepancies in diabetes family responsibility, in T1DM	Quantitative, cross-sectional. (Self-report questionnaires)	Perceptions of family responsibility for self-care tasks and parental confidence in adolescents' self-management have implications for parental diabetes distress.

Table 2 continued

Ness et al. (2018) (United States) [21]	N=9 mothers of college bound emerging adults with T1DM.	To gain a deeper understanding about mothers' experiences of transitioning their emerging adult with type 1 diabetes mellitus to college	Qualitative, descriptive. (Interviews).	Mothers of emerging adults with T1DM experience heightened levels of concern during the college transition above and beyond those that are experienced by mothers of emerging adults without T1DM.
Sullivan-Bolyai et al. (2014). (United States) [33]	N=23 parents and teens: mean age of adolescent 14.9.	The purpose of this exploratory focus group study was to describe the perspectives of teens and their parents about self-management knowledge, behaviors (including division of labor associated with T1DM management), and resources used to manage T1DM.	Qualitative. (Focus groups).	Teen and parent perspectives are critical in designing future well-received adolescent–family transition clinics.
Ersig et al. (2016). (United States) [29]	N=40 teens and parents: mean age of teens not indicated.	The purpose of this study was to identify stressors of teens with T1DM and their parents related to the impending transition to adulthood.	Qualitative, descriptive. (Interviews).	Teens with Type 1 diabetes and their parents understand that independent teen self-management is a component of transition to adulthood but worry about teen self-management outcomes.
Hessler et al. (2016). (United States) [30]	N=332 parents and providers: mean age of adolescents 15.33.	To identify the unique areas of diabetes-related distress (DD) for parents of teens with type 1 diabetes and parent and teen characteristics associated with DD.	Cross-sectional.	Diabetes distress was associated with family demographic, teen diabetes status, and parent contextual factors, and can help identify parents who may be more vulnerable to DD.

The majority of the studies were conducted in the United States (U.S.) (n=4), with the remaining studies from the United Kingdom (U.K.) (n=1), Ireland (n=1), and Denmark (n=1). Studies focused on issues related to T1DM distress of the parent

and/or youth (n=3), healthcare transition from pediatric to adult providers (n=2), self-management issues (n=1), and the parent perspective of transition to college with T1DM (n=1). Parent sample sizes ranged from 203 to 332 in quantitative studies and 9 to 25 in the qualitative studies. Youth sample size ranged from 6 to 10 in the qualitative studies while the quantitative study that included youth participants had a sample size of 203. The mean age of parents, reported in three studies, was 47.5 years old and the mean age of youth, reported in three studies, was 15.5 years old. Three studies reported marital status with 75% of couples being married; parental race or ethnicity was rarely reported in any of the studies. Researchers identified four overarching themes reflecting the experiences of parents as they prepare to transition to the next stage of parenting their youth with T1DM.

### **Developing and Promoting Autonomy**

Transitioning from parenting an adolescent to launching an adult is a complex time in a parent's life. These challenges are heightened in the presence of T1DM. Parental support of their youth as they strive to attain independence in their T1DM management will facilitate the transition to the next life stage for both parent and youth; however, parents commonly report concerns about their youth's ability to self-manage their condition.[28,29] In a U.S. study, parents and youth (mean=15.3±2.27 years) reported that as primary responsibility for T1DM management transferred to adolescents, the frequency of blood glucose monitoring decreased ( $t[146]=4.43$ ,  $p<.001$ ) and hemoglobin A1C increased ( $t[146]=2.89$ ,  $p<.01$ ) over 6 months.[30]

In dyadic studies conducted in Denmark, Ireland, and the U.S., youth reported that while they saw the transition of T1DM management as a physical rather than emotional change, they shared similar concerns regarding the development of self-

management skills and the increased risk for hypoglycemia.[28,29,31] As parents and youth begin the transition process, the responsibility for T1DM management tasks shifts from caregivers to youth.

Parents identified several challenges to the promotion of autonomy and self-management behaviors including resource limitations, the inability of youth to self-manage,[31] increased distress for both parents and youth related to T1DM family responsibility disagreements when both family members claim responsibility, and parents' perception of reduced adolescent self-efficacy.[32] In a study of 332 parents focused on T1DM-related stress, 88.9% of parents indicated that they experienced at least “a little” distress and 56.9% indicated “moderate” or higher levels of distress related to concerns about youth T1DM self-management.[30] In a qualitative study conducted in Ireland, parents indicated that their involvement in T1DM management was still required, yet it was not accommodated in the transition program.[31]

Limited access to healthcare professionals (HCPs) may inadvertently create barriers to the attainment of autonomy. In dyadic studies, while both parents and youth reported receiving helpful information from T1DM clinic staff, there was a desire for HCPs to take a more holistic, youth and family-centered approach to T1DM management and be less focused on blood glucose levels.[33] Parents also reported that while they felt it necessary to make sure their youth was self-sufficient in self-management, they felt pressure by HCPs to physically do the care; some even reported that they were threatened with social services referrals, defeating parental attempts to promote autonomy.[33] This angered both parents and youth and led to a fear of being honest with HCPs.[33] Parents indicated they would like more information about how to plan for college and manage T1DM in the college setting.[34] Parents and youth

both report that coming home for T1DM management is a barrier, as college is perceived as taking priority over appointments; however, youth who move away for college may have difficulty obtaining necessary support from HCPs on or near campus.[31]

### **Evolving Relationships and Roles in the Parent/Youth Dyad**

In order for parents and youth to successfully transition to the next stage of life, parents must transfer responsibility for T1DM management to their youth. As youth become more independent with T1DM self-management, changes in the parent/youth dyad may leave parents unsure of their role in their youth's T1DM management.[29,33] While parents are aware of their changing relationship, parents of youth without continuous glucose monitors felt particularly isolated due to lack of communication about T1DM management from their child.[20] This feeling of isolation was not unique. This left mothers of youth with T1DM with heightened levels of concern including shifting roles in the parent/youth dyad and changing communication dynamics.[21]

Parenting styles were noted to impact the parent-youth relationships. A qualitative study conducted in the US found that parents of youth age 13-17 generally fell into three different parenting styles with regard to T1DM management: "taking the lead" (parent maintaining control), "striking a balance but still in the driver's seat" (allowing youth self-management, but providing oversight), and "backing off" (allowing youth to take over control).[34] Another quantitative study found that parents who employed an authoritarian parenting style reported significantly increased levels of T1DM distress and greater strain on their relationship with their youth.[30] Parents who "backed off" reported that they were aware that their youth (age 13-17)

were not in good control of their T1DM but felt that it was necessary to allow them to learn how to self-manage, with one participant indicating “I am not always going to be here and he needs to know how to care for himself. That is my job as a parent”.[33 p187]

### **Distress**

Both qualitative and quantitative studies indicate that lack of support for parents leads to higher levels of distress related to T1DM management.[21,30,31] A quantitative study of 332 parents in the US indicated that sources of parental T1DM distress included personal distress, youth management issues, parent/youth relationship dynamics and concerns about the healthcare team.[30] Parental T1DM distress was statistically significant and higher among fathers, younger parents, and those without a partner. Parents of youth with higher hemoglobin A1c levels and those reporting less emotional support as well as depressive symptoms (as reported by the General Life Stress Scale) reported statistically significant increases in distress related to their child’s T1DM.

A quantitative dyadic study conducted in the UK echoed these concerns. Parents of youth age 12-18 with higher hemoglobin A1c had higher levels of parental distress ( $r=.26$ ,  $p<.001$ ).[32] Additionally, parent distress was positively correlated with youth distress ( $r=.46$ ,  $p<.001$ ) and with disagreements about responsibility between parent and youth when both assume responsibility.[32] Conversely, lower levels of parental distress were associated with higher youth self-efficacy ( $r=-.28$ ,  $p<.00$ ),[32] higher parental perceptions of youth self-efficacy ( $r=-.43$ ,  $p<.001$ ),[32] and increased agreement of responsibility for T1DM self-management activities ( $r=-.21$ ,  $p<.01$ ).[32]

Parents indicated that, despite taking steps to ensure that their youth could manage their T1DM management on their own, they continue to worry.[21,29,30] Research showed that while both youth and parents have concerns about the future, parents are more anxious, particularly when they felt excluded from their youth's management.[28,31] This was particularly true for youth who were preparing to go away to college. One youth stated "I want to go away (to college), but then I know my mother won't be there to help me...I worry about it, too, like just not having my mother to fall back on...I feel like I depend on (her)".[29] Parents of college bound youths with T1DM have concerns that are above and beyond those of parents of youth without a chronic condition.[21] One mother noted "I don't think anyone with a kid without a chronic illness could really understand the level of that fear. If she was just going off to college as a kid, my concern might be more about drinking or sexual harassment, but because of the T1DM, I think that my concern starts with just her staying alive." [21 p182]

### **Discussion**

Parents of college bound youth may have unique concerns. The parental transition from parenting an adolescent to launching an adult is a complicated period in a parent's life. Parents may view their youth's departure as a test of their parenting skills and a reflection of their abilities as parents.[4,5] This parental transition happens concurrently with their youth's transition from adolescence and may be the catalyst for great change within the family; it changes the balance of relationships in those who remain in the home and may lead parents to question their role in their child's future.[5] This change may be more significant in families of youth with T1DM. Parents and youth report concerns with youth's ability to self-manage their

T1DM.[28,29], and given that hemoglobin A1c increases and blood glucose monitoring decreases as youth assume T1DM management responsibilities, these concerns are often well-founded.[30]

A high level of worry or concern may inhibit parents from supporting their youth to gain the skills necessary to manage their T1DM due to low perceived youth self-efficacy as well as the immediate and long-term negative outcomes of youth self-management.[21,28,29] Research reviewed clearly demonstrated that parental support for youth transitioning with T1DM is an integral part of the transition process,[28–31,33] but few studies focused on parents’ needs as they attempt to support their youth during their move towards self-management. Parents express concerns and worry about their youth regarding T1DM management and the multiple distractions at college; [21,29] thus, many parents restrict the college choices or delay their departure from home to ensure proximity to HCPs.[29] This worry is pervasive among parents of college bound youth with T1DM. One mother noted “when she goes to college...is she going to be doing what she needs to do, or is she going to be out partying and drinking and doing that stuff that she shouldn't be doing that college kids do?”[29 p393]

While the T1DM literature reviewed discusses stressors related to the promotion and development of autonomy,[28-33] no studies focused specifically on support for parents as they move their youth towards autonomy. This is significant as parents who are able to manage their own transition to parent of a college-bound youth with T1DM may have decreased levels of stress during this time, which, in turn, may support a positive transition for both parent and youth as they move to the next stage of life.[3,20]

When youth with T1DM leave home for college, the transition may be somewhat more complicated. Despite potentially living away from the family home, college students are still somewhat dependent on parents, with many youth still relying heavily on parents for assistance in T1DM management both economically and psychosocially.[21,29] This dependency of convenience, coupled with the fact that college students typically return home during winter and summer breaks, may serve as both a facilitator and a barrier to a parent's ability to transition themselves to the next stage of life.[30] Continued quasi-dependence may cause parents of youth with T1DM who live on campus during the school year to struggle with establishing who is responsible for T1DM management given the transition of the youth in and out of the home during this time.

The relationship between parent and youth has been shown to be a powerful mediator for transition, facilitating better glycemic control and compliance; however parental over-involvement may be counterintuitive to youth assuming full responsibility for their T1DM management.[19] Parents who feel that their youth is not capable of managing their T1DM management and/or who do not feel supported as their youth move to the college setting may be reluctant to allow their youth to self-manage, potentially leading to overparenting.[30,33] While an authoritarian parenting style has been found to increase parental distress, an authoritative parenting style has been shown to promote compliance in adolescents, indicating that helping parents to see the difference may be an effective way to facilitate the transition process.[30,33]

Parents and youth were found to share the same concerns of safety, attaining normality, striving for independence, and worry about the future, though each experienced the concern in isolation.[28] Overall lack of support for parents of youth

with T1DM during the transition process leads parents to feel isolated and “left out” of their youth’s transition, increasing overall distress at this critical time in parents’ lives.[21,30,31] Isolation was not uncommon, as parents of youth with T1DM reported that as their youth moved towards adulthood, they were increasingly excluded from HCP visits.[31] While research indicates potential sources of T1DM distress for parents, more studies are needed to explore the psychosocial implications of this level of distress on parents’ own transition. Parents of youth without continuous glucose monitors felt particularly disconnected from their youth’s T1DM management as they were not readily able to monitor their youth’s blood glucose level.[21] It could be assumed that technology (continuous glucose monitors, cellular phones, etc.) would be a significant contribution to the development of autonomy and a potential mediator of parental distress, but there was limited reference to technology in the reviewed literature.[21]

Limitations of this review include the small number of studies included, with 40% (n=4) focused exclusively on the transition from pediatric to adult health care. Only one study focused exclusively on the parent perspective of transition of their youth to college. Even though CGM technology has been available for 20 years, there was very limited discussion of technology in any of the literature reviewed, despite what would appear to be a significant impact on the transition process. Only two studies took a longitudinal approach. This integrative literature review does not take into account youth who attend college but live at home with parents during the school year, health status of parent, family structure, income, race of parent or child, or employment status. Additionally, the number of children in the family and birth order were not considered.

## **Conclusion**

Current research findings yield a lack of clarity regarding the needs of parents during the transition and how that may facilitate their children's transition to college. While research has demonstrated that continued parental involvement in diabetes management predicts better outcomes, few studies focus on the barriers and facilitators that promote a positive transition for parents as they work to move from parenting an adolescent to launching their youth with T1DM to transition to college. Limited research on parents indicated that those who gradually allow their youth more autonomy while continuing to feel that they are able to parent meaningfully through the transition will experience less anxiety and be more likely to successfully transition themselves. This suggests that clinicians working with parents of college-bound youth with T1DM may want to consider the parent perspective and potential support needs during the transition, as family life cycle theory suggests that successful transitioning may prevent disease and emotional or stress-related disorders. Delaying the transition process for parents may lead to unresolved psychosocial and physical health crises including difficulty with relationships and future transitions. More research is needed to determine the barriers and specific interventions that promote a positive transition for parents of college-bound youth with T1DM. This research could provide important information that will not only assist parents to transition successfully to the next stage of life but may lead to better health and quality of life for both parents and youth.

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**Findings from this study indicate that gaining the perspectives of youth with T1DM and their parents is critical in designing future well-received adolescent–family transition clinics.**

## Chapter 3

### **EARLY TRANSITION: MATERNAL EXPERIENCE OF TRANSITIONING THEIR EMERGING ADULT WITH TYPE 1 DIABETES TO COLLEGE**

The information in this chapter is adapted, with permission from Sage Publishing (Appendix B), from Maternal experience of transitioning their emerging adult with type 1 diabetes to college by M. M. Ness, J. L. Saylor, and J.A. Selekman, published in *The Diabetes Educator* (Volume 44, Issue 2, pages 178-187, April 2018). M. Ness was responsible for the conception and design of the study; the acquisition and analysis of data; drafting and revising the manuscript; and approval of the version of the manuscript to be published. J. Saylor was responsible for the analysis of data; revising the manuscript; and approval of the version of the manuscript to be published. J. Selekman was responsible for revising the manuscript and approval of the version of the manuscript to be published.

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## **Abstract**

The purpose of this study was to gain a deeper understanding about mothers' experiences of transitioning their emerging adult with type 1 diabetes mellitus (T1DM) to college. A descriptive, qualitative study was conducted with nine mothers of high school seniors with T1DM using semi-structured questions via recorded telephone interviews. Among the nine participants, eight had daughters and one had a son. The thematic analysis resulted in four themes: 1) concern for health and safety at college; 2) evolving roles of the parent and emerging adult dyad; 3) communication dynamics; and 4) social support systems. Results indicate that mothers of emerging adults with T1DM experience heightened levels of concern during the college transition. These concerns are above and beyond those that are experienced by mothers of emerging adults without T1DM. Findings indicated that increasing levels of support for both parents as well as emerging adults with T1DM during the college transition may serve to decrease maternal stress and enhance the development of preparedness for diabetes self-management. Recommendations for diabetes educators in clinical practice include a family-centered approach focusing on the transition before the late adolescent period, interventions from colleges to promote a smooth transition as well as interventions that address concerns of both the emerging adult with T1DM and the parent. Further research is necessary to identify barriers and facilitators to support parent/emerging adult dyads during the college transition period.

Keywords: Type 1 Diabetes Mellitus, Transition, College, Parents, Qualitative

## Introduction

Type 1 diabetes mellitus (T1DM) affects approximately 193,000 youth under the age of 20 in the United States;<sup>1</sup> the rate is increasing by 1.8% each year.<sup>2</sup> As over 20.4 million students are expecting to attend college in 2017,<sup>3</sup> it is clear that more emerging adults with T1DM will be transitioning to college in the near future. The transition to college is a pivotal period for emerging young adults, defined as 18-25 years of age,<sup>4</sup> and it may be more challenging for families with an emerging adult with a chronic condition such as T1DM. Management of T1DM requires a complex series of blood glucose checks and multiple daily insulin injections, monitoring of diet and physical activity patterns, and responding to episodes of hypoglycemia or hyperglycemia.<sup>1</sup>

Some college students with T1DM struggle with independently navigating the many facets of college life that may impact T1DM management, including academics, sleep, nutrition, and physical activity as well as the potential for engagement in risky behaviors and the development of mental health issues.<sup>5-7</sup> Complicating this transition are the health-related, behavioral, and developmental changes that result from the transition from attending high school and living at home with parents to going away to college and living independently.<sup>8,9</sup> Lifestyle modifications may be especially challenging for emerging adults who did not independently self-manage their disease prior to leaving for college.<sup>1,10,11</sup> College students with T1DM report higher levels of psychological distress, especially anxiety regarding their diabetes, than college students with other chronic conditions, such as asthma or allergies.<sup>12</sup> In college, emerging adults are at increased risk of poor glycemic control, loss to follow-up care, acute complications, psychosocial issues, and sexual and reproductive health issues.<sup>8,13</sup>

Additionally, involvement in high risk activities such as alcohol use, smoking, and drug abuse worsen glycemic control placing youth at risk for immediate and long-term diabetes complications.<sup>13,14</sup>

While parents are integral in their support during the expected college transition, a gradual shift of T1DM management from partial dependence to independence on the part of the emerging adult is imperative to prevent complications related to diabetes. Developmentally appropriate interventions by the diabetes care team and the family ultimately lead to a successful transition.<sup>15-17</sup> Interventions may include requesting necessary accommodations to modify living arrangements and ensuring that students with T1DM have an equal opportunity to be successful at college. The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 (Section 504) continue to provide protection for students with T1DM in the post-secondary setting. However, accommodation requests must be made in writing by the student and not the parent.<sup>18</sup> This may further complicate the transition process, particularly if the student has not been actively involved in their Individualized Education Program (IEP) or Section 504 Plan (504) process during high school.

T1DM management is positively influenced by parental support as well as mutual respect between parent and the emerging adult.<sup>19-23</sup> As parental support decreases, emerging adults' autonomy and responsibility for their T1DM self-management increases.<sup>24</sup> This transition to self-management may add to existing stressors as emerging adults concurrently progress through both developmental changes and diabetes-specific tasks in the college environment with its different challenges.<sup>25</sup> This increased stress, combined with the somewhat undefined role of

parents during the transition may lead to depressive symptoms in parents and challenges with glycemic control in emerging adults.<sup>26</sup> Additionally, the transition from a pediatric healthcare provider to an adult healthcare provider may lead to loss of follow up care, indicating that diabetes distress may need to be addressed in the clinical setting and may be viewed as a barrier to successful transition.<sup>27-31</sup>

While most research focuses on the transition process in emerging adults with T1DM, there is a lack of research on the parents' role in T1DM management as well as their concerns during this time period. As per the Revised Self and Family Management Framework,<sup>32</sup> understanding the experiences of parents as their emerging adult transitions to college, especially the barriers and facilitators, may assist in the developing effective interventions. Therefore, the purpose of this qualitative study is to gain a deeper understanding of maternal experiences of transitioning their emerging adult with T1DM to college.

## **Methods**

### **Research Design**

A descriptive, qualitative research design was conducted using semi-structured interviews to gain a deeper understanding of this phenomenon of parents transitioning their emerging adults with T1DM to college.<sup>33</sup> This study was approved by the University of Delaware Institutional Review Board (IRB; Appendix C).

### **Sample**

A purposeful sample of nine participants was enrolled in the study using the snowball sampling technique and the College Diabetes Network Facebook page. An IRB-approved advertisement was posted on the College Diabetes Network Facebook

page and emailed to potential participants with a link to the online consent and demographic survey. Recruitment took place between March 2017 and May 2017. Eleven individuals indicated interest by completing the informed consent; however, two participants failed to schedule an interview. All participants were parents of high school seniors with T1DM who were going to college in the fall of 2017. For this study, a parent was defined as a biological or adoptive parent, stepparent, legal guardian, or parental figure. Participants were required to speak and read English.

### **Setting**

Telephone interviews were conducted by a school nurse administrator using a data collection protocol that included the study introduction and semi-structured interview questions. Participants were able to speak freely beyond the interview questions. Interviews lasted approximately one hour and were conducted using a recorded toll-free conference phone service allowing participants to contact the researcher at the prearranged time. The telephone interviews were conducted in a private office and were transcribed verbatim by a professional transcriptionist.

### **Data Collection**

Interested parents completed the informed consent and a demographic questionnaire via REDCap (Research Electronic Data Capture)<sup>34</sup> that also included contact information for scheduling the interview. Participants' confidentiality was maintained throughout the process by removing all names and using aggregate coding and fictitious initials in the results. Participants were asked about their experiences with transitioning their emerging adult to college. Seven semi-structured questions focused on the parent's perspectives on the transition experience (See Table 3).

Table 3 Semi-structured interview questions

1. What concerns do you have about your child with type 1 diabetes going to college?
2. Think about something related to your child's diabetes that has been difficult for you in the last month, and describe it to me, please.
3. Tell me about your involvement with your child's diabetes management in the past month? The past year?
4. How do you think your child feels about their diabetes? How do they feel about leaving for college as it relates to their diabetes?
5. What are your thoughts about how your child will manage their blood glucose while away from home?
6. How are you helping to prepare your child for their transition to college?
7. What resources would be helpful to you as you help your child transition to college? What resources would be helpful to your child?

### Data Analysis

Two researchers read the verbatim transcripts independently and conducted the systematic thematic analysis. The initial coding process involved reviewing the transcribed interviews line by line. Emergent ideas and key concepts were grouped and noted to aid in the identification of initial categories; this created a digital audit trail that served as the foundation of the validation strategy.<sup>35</sup> Once the initial interpretation of the data was complete, a list of 25-30 tentative codes was applied to identify themes in the narrative data.<sup>35</sup> Similar codes from the list were aggregated and quantified to create three initial themes. Intercoder agreement was established by using an iterative process of re-coding, re-reading, and re-analyzing transcripts; this yielded four final themes and subsequent sub themes.<sup>36</sup> For the final phase of thematic analysis, the authors chose participant examples for each theme as it related to the purpose of this study.

## **Data Trustworthiness**

In qualitative research, trustworthiness consists of the following components: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability.<sup>35</sup> To increase data credibility, triangulation was achieved by locating evidence of a privacy code on both the demographic questionnaire (parental involvement: privacy) and in the interview (parental involvement: hovering or spying) by confirming that the children did indeed have electronic diabetes equipment and that it was not otherwise connected to a device to which the mother has continual access.<sup>35</sup> Also, participants consented online and verbally to be contacted again in order to receive their feedback. Transcripts were returned to participants for review, but participant feedback on findings was not solicited.

Transferability was achieved by using a purposeful sample of mothers with young adults who were seniors in high school and attending college in the fall.<sup>35</sup> The sample was obtained using the College Diabetes Network. This study provided a detailed research process description that increased the data transferability and trustworthiness. Results were derived from continuously referencing the original transcripts and comparing information gleaned to ensure that clear connections to the data were evident. These initial codes were used in the second reading of the transcript and were built on as the meaning of the words was reevaluated with a more informed lens.

An inquiry audit was conducted by an experienced qualitative researcher to establish dependability and confirmability simultaneously.<sup>35</sup> The auditor examined the complete process of inquiry from beginning to end. Dependability of the inquiry process was determined after examination of the research documentation and the process of the interview.<sup>35</sup> Finally, confirmability was achieved when the findings,

interpretations, and recommendations were supported by the interview data.<sup>35</sup>

Reporting of methods, analysis, and study results followed the consolidated criteria for reporting qualitative research (COREQ) checklist.<sup>37</sup>

## Results

All study participants (n = 9) were white, non-Hispanic, biological mothers who were married. The participants held a bachelor's degree with 44% earning a graduate degree. Participants' household size ranged from three to five people including themselves (see Table 4). Emerging adults were all diagnosed with T1DM between 3 and 10 years of age with a mean of 6.89 ( $\pm 2.71$ ) and were the first in the family with T1DM to go to college (see Table 4). Thematic analysis resulted in four themes with subsequent sub-themes: 1.) concern for the emerging adult's health and safety at college, 2.) evolving roles in the parent/emerging adult dyad, 3.) changes in the communication dynamic, and 4.) developing support systems for the parent and emerging adult. Parents of emerging adults with T1DM generally feel that their concerns are greater than and different from those of parents of emerging adults without a chronic condition.

Table 4 Sociodemographic characteristics of study participants (n=9) and their senior high school students with type 1 diabetes who are college bound (n=9).

Mothers	n (%)
Education level	
Bachelors	5 (56%)
Advanced degree	4 (44%)
CDN Awareness <sup>a</sup>	
Yes	8 (88%)
No	1 (11%)

Table 4 continued

Campus with CDN	n (%)
Yes	2 (22%)
No	3 (33%)
Unsure	4 (44%)
High School Seniors	
Gender	
Male	1 (13%)
Female	8 (87%)
Insulin pump	
Yes	7 (77%)
No	2 (22%)
CGM <sup>b</sup>	
Yes	7 (77%)
No	2 (22%)
Shared Technology <sup>c</sup>	
Insulin pump	
Yes	2 (22%)
No	7 (77%)
CGM	
Yes	6 (66%)
No	3 (33%)
Accommodations	
High School (504 plan)	6 (66%)
Plans to apply in College	5 (55%)
Unsure about college	4 (44%)
Provider at college	
Pediatric endocrinologist	5 (55%)
Adult endocrinologist	2 (22%)
Unsure	2 (22%)
Specialists seen during senior year	
Endocrinologist	9 (100%)
Pediatrician	6 (66%)
Primary Care Provider	2 (22%)
Psychologist	2 (22%)
Gastroenterologist	1 (11%)
Other	5 (55%)

Table 4 continued

Doctor's office visits past year <sup>d</sup>	
1-4	7 (77%)
5-8	2 (22 %)

*Note.* <sup>a</sup>CDN=College Diabetes Network. <sup>b</sup>CGM=Continuous Glucose Monitor. <sup>c</sup>Technology Shared with Parents indicates that parents have access to insulin dosing and glucose results via cellular phone. <sup>d</sup>Number of visits included routine and nonroutine.

### **Theme 1: Concerns for Health and Safety at College**

The first theme that emerged is an overarching concern for their emerging adult's safety at college. This worry manifests itself in two distinct subthemes: physiological concerns and level of preparedness. All participants indicated they had concerns about their emerging adult's blood glucose control, with several participants indicating that they were very worried about their child's blood glucose level dropping in the middle of the night, leading to serious consequences, including death. VK stated:

I don't think anyone with a kid without a chronic illness could really understand the level of that fear. If she was just going off to college as a kid, my concern might be more about drinking or sexual harassment, but because of the diabetes, I think that my concern starts with just her staying alive.

#### Physiological concerns.

There was a universal fear for their emerging adult's safety. Participants indicated that while their emerging adults were excited to begin a new chapter in their lives, the participants themselves were primarily concerned with their emerging adult's hypoglycemic reactions and their ability to manage their diabetes away from home. Students with poor glycemic control may not perform as well on tests and other assignments, so proper management is imperative. KO stated:

My child is not in that good of control, so I have real concerns about how high her blood sugar might get. Her A1C right now was 9.2. I've heard that A1Cs tend to go up for kids in college, so I'm concerned about just how high in the double-digits it will go.

Preparedness.

Preparedness is a common theme, reflecting both the parent's level of readiness for the change as well as how well they perceived their emerging adult to be prepared to self-manage their diabetes when they to go to college. EN noted that even though emerging adults are required to take responsibility for their diabetes, the worry will not end. After expressing concerns about the emerging adult's level of preparedness to transition to college, she stated:

Her endocrinologist clearly said to me this is her disease. She's going off on her own, she's got to be the one to manage it [...]. You're kind of powerless and all you can do is worry. You can't manage, you can just worry, whereas at least while they're in your care, you can play a little bit of a role in management. Once you let them go, it's totally up to them.

Parents of emerging adults with T1DM appeared to understand that their emerging adult should be taking responsibility for their care. All indicated that their child was assuming at least some level of responsibility for their care. VK noted:

We're not ready yet. I'm a terrible planner, and so I feel like in the weeks prior, we'll be going through the rigmarole of prescription renewals, and packing things into crates..., but she doesn't worry herself that much with that, and I think she has a lot of confidence in the medical equivalent of Amazon Prime.

## **Theme 2: Evolving Roles in the Parent and Emerging Adult Dyad**

The mothers had a sense of awareness that their relationship with their emerging adult would be changing over the next several years and that it would focus more on their emerging adult rather than their diabetes. The average age at diagnosis

for the emerging adult in this sample was approximately 7 years old, indicating that participants had been caring for their emerging adult with diabetes an average of 10 years. Participants all acknowledged the fact that their role in their emerging adult's diabetes care had changed over the course of the past year and would continue to change, with the goal of total independence in mind. This transition to self-management takes many different forms, including struggles with relinquishing control, with participants reporting varying levels of current involvement with diabetes management. CL stated:

My involvement now is I help her. I do a lot of time the site changes for her insulin pump because sometimes they're in awkward-to-reach places for her; so every couple days I do that for her [...]. That's the extent of my involvement.

While all participants acknowledged that their role in their emerging adult's diabetes management would continue to change over the next several years, those whose children did not have continuous glucose monitors felt particularly isolated as there is a lack of connectedness to their emerging adult's current level of diabetes self-management. CL stated:

If she's not around, there's absolutely nothing I can do because obviously I can't text her and just say what's your blood sugar, because that would just be too invasive. When we went to her endocrinologist, they clearly said to me this is her disease.... She's got to be the one to manage it, so I can't be a helicopter parent, so I try to distract myself by doing something that I have to really concentrate on so I won't think about it.

#### Relinquishing control.

While participants are accustomed to providing care for their emerging adults with T1DM, there was a growing need to relinquish control and transition diabetes management to the emerging adult. However, participants reported that emerging

adults still viewed their parents as their “safety net”, which rightfully concerned participants who were acutely aware that they would not always be there to intervene. Despite the clear need to transition care to their child, one participant reported that she and her husband had “put their foot down” and informed their emerging adult, who does not currently wear a CGM, that she would not be able to go to college unless she agrees to wear a CGM. However, this level of control may not serve to foster the level of independence necessary to take over self-management.

MB reports that her emerging adult, who will be attending college close to home, seems to feel that diabetes management will still be taken care of by a parent. This highlights the need to initiate focused conversations between parent and emerging adult regarding how care will be relinquished to the emerging adult and to delineate responsibilities during the transition process:

She’s only an hour away from us, so she’s just assuming still that everything will be handled for her. We did have an incident in the past 5-6 months where we were on a family vacation and she just assumed that I took care of everything, but she wasn’t prepared. That was kind of an eye opener for us and a good dialog for us to talk to her about; that she can’t always just assume just because I’m there that I’m going to be her backup.

### **Theme 3: Changing Communication Dynamics**

Participants found discussion about diabetes with their emerging adult to be challenging. Emerging adults are generally resistant to talk about their diabetes and even more resistant to discuss their self-management with their parents. Rather than directly asking their emerging adults about their self-management, more than one participant reported routinely sneaking into her emerging adult’s belongings to check diabetes record keeping, including their continuous glucose monitor and/or insulin

pump, noting “That's not to say that in the middle of the night I don't grab her meter and look at what she was when she went to bed.” CT stated:

One thing that I'll do is I'll just go into her kit and just look at her meter and go through the record keeping that it does so I can see like, OK, this is what you were before lunch and that you tested at the end of the school day before you drove home and what your numbers look like over the past couple weeks.

Given the nature of teenagers, this lack of communication regarding their life-threatening condition can make navigating the transition challenging. AB stated, “I do not talk to her about it because it ... makes her uncomfortable. I don't want to say it gives her anxiety because that's not really true but it makes her really uncomfortable.” In this case, the participant was hesitant to express concerns to her emerging adult, potentially creating further barriers to healthy communication that may facilitate the transition process. VH noted:

I think that more and more our conversation won't center around her numbers and her care and her needs, and they'll be more about her, and maybe our relationship will kind of morph into something that is less about her diabetes, which would be very welcome; I would welcome that really hugely. I don't know what a relationship is like when it isn't about diabetes anymore.

#### **Theme 4: Need for Support Systems**

Several participants indicated that a support group would be very helpful for them as they work to transition their emerging adults to self-care away from home. Available support appears to ease participants' minds about their emerging adult's well-being at college. Parents felt that the availability of a “teens in transition” group would help their emerging adult connect with other students with T1DM on campus, thus providing a network of support to assist their emerging adults, and ultimately alleviate some stress for participants during the transition process. AB stated:

One thing I think would be helpful for me and for her, and I'm going to look into this with our next doctor's appointment because I think they offer one of these teens-in-transition type of seminar or meeting, and I think that would be obviously helpful for her.

Participants worry about their emerging adults being so far away with limited support. Despite the fact that there are supports offered for students at college, parents indicated that they would like some level of support for assistance in case of an emergency. MB shared that she would feel more supported if she was able to identify individuals who were willing to provide assistance when necessary, stating, "I need a plan of action. I need people who are willing and I know it's asking a lot. I need to know there are people who are willing to help her if we get into a situation." To this end, CT noted:

It suddenly occurs to me: what are we going to do when she is 2,000 miles from us and our phones start alarming and we call and we can't get a hold of her? I just felt sick to my stomach because I just thought, okay, I get it. I'm going to have to have a framework of support. Unfortunately, she's going to a town where we don't know anyone within five hours.

## **Discussion**

The purpose of this study was to examine the experiences of mothers as their high school senior with T1DM prepares to transition to college. Themes identified illustrated the factors impacting the transition process for these mothers: the transfer of diabetes management tasks and coping with their concerns about what might happen when their emerging adult is in college. The themes focused on the relationship between the mother and emerging adult and how that relationship is evolving during the transition process.

All participants expressed concern about their emerging adult becoming hypoglycemic in the middle of the night. This concern vastly outweighed any other

concern related to their emerging adult going to college. Another concern was the risk of extremely high blood glucose levels due to poor self-management skills. Despite potential poor self-management, participants were generally optimistic that their emerging adult would successfully meet the challenges normally experienced by college freshmen.<sup>5-9</sup>

Participants noted typical concerns of college transition including grades, risky behavior engagement, peer pressure, and developing a social network. However, participants reported that their emerging adults vary in their level of preparedness for the transition to college as it relates to their diabetes self-management. Participants also worried about distractions, such as school work and social life that may distract their emerging adult from proper self-care habits. Participants indicated that their emerging adults tended to be very private about their diabetes and did not wish it to be a constant topic of discussion, leading to increased stress among the mothers.

While the mothers acknowledged their own stress and concerns, none addressed the psychological distress their emerging adult might be experiencing regarding managing and dealing with their diabetes during their freshman year.<sup>12</sup> Most participants indicated that they had no specific plans in place to discuss the transition, nor had they taken many steps to prepare. Some mothers indicated that either they or their emerging adult had contacted the office of disability services at their college, receiving varying levels of information regarding potential accommodations available on campus.

### **Recommendations for Research and Clinical Practice**

While the current study highlights the concerns that educated mothers have as their emerging adult transitions to college, it may not be generalizable to other

populations. This study did not address paternal and family concerns, which may be different than maternal concerns with young adults with T1DM. This study may not be generalizable to parents of emerging adults with type 2 diabetes or those who are directly entering the workforce or those who are not under the care of established endocrine practices.

Mothers voiced the supportive advice given to them by their diabetes provider to prepare for the transition; however, none indicated that they had been provided with information specific to the college transition. The Revised Self and Family Management Framework<sup>34</sup> could be used to assist diabetes educators and other providers to create interventions that focus on the enhancement of facilitators to self-management in emerging adults, specific to the college setting. The Framework identifies facilitators and barriers that may influence the ability to self-manage as well as self and family management outcomes.<sup>34</sup> Knowledge of the maternal perspective of the transition process will allow for more targeted interventions that will facilitate proximal outcomes, such as positive emerging adult self-management behaviors and a better understanding of the transition process as well as distal outcomes including improved emerging adult health status at college and improved family outcomes. In clinical practice, diabetes educators can facilitate this process by working with mothers to alleviate fears that may prevent them from relinquishing control to their emerging adults.

Diabetes organizations that focus on college students may partner with endocrine practices as well as campus student services departments to share information about college transition to inform practices aimed at supporting college students with T1DM. This may serve to alleviate transition concerns by addressing

barriers to self-management at college and to promote continuity of care for emerging adults. Diabetes educators and disabilities services offices should work together to create accommodation plans prior to the emerging adult's arrival on campus that could potentially decrease some of the maternal concerns and assure the availability of a resource to contact in case of emergency. The insight gleaned from these findings can serve to provide valuable information about the maternal perspective of the transition to college as well as identify potential areas of improvement for campus student services departments.

### **Conclusion**

As more youth with T1DM plan to attend college, the preparation process for these emerging adults and their parents should be evaluated for relevance and adequacy. Recognizing parental concerns is essential in order to implement a smooth transition plan. Parents serving as a "safety net" for their emerging adults is not uncommon; however, as emerging adults with T1DM approach adulthood, the need to take over their own care is paramount. Mothers must take an active role in the transition planning process to foster independence in emerging adults as well as alleviate fears that may prevent mothers from relinquishing control. Further research is necessary to identify barriers and facilitators as well as interventions that will support parent/emerging adult dyads during the college transition period.

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## Chapter 4

### **LATE TRANSITION: BARRIERS AND FACILITATORS EXPERIENCED BY PARENTS OF EMERGING YOUNG ADULTS WITH TYPE 1 DIABETES MELLITUS DURING THE TRANSITION TO COLLEGE:**

This chapter constitutes an initial draft of a manuscript for submission to the Journal of Adolescent Health (Impact Factor: 3.612). M. Ness was responsible for the conception and design of the study; the acquisition and analysis of data; drafting and revising the manuscript; and approval of the version of the manuscript to be published. J. Saylor was responsible for the analysis of data; revising the manuscript; and approval of the version of the manuscript to be published. J. Selekman was responsible for revising the manuscript and approval of the version of the manuscript to be published.

The Journal of Adolescent Health is the official publication of the Society for Adolescent Health and Medicine. The journal aims to publish new research findings in the field of adolescent medicine and health ranging from biological and behavioral sciences to public health and policy.

## Abstract

**Purpose:** The purpose of this study is to gain a deeper understanding of the facilitators and barriers experienced by parents of emerging young adults (EYAs) with type 1 diabetes (T1DM) who have completed their freshman or sophomore year of college.

**Methods:** Using a descriptive, qualitative design, sixteen parents participated in semi-structured interviews that explored factors impacting the college transition for parents of college freshmen and sophomores with T1DM. Participants were recruited from local endocrinology clinics as well as the College Diabetes Network (CDN) Parent Facebook page, the CDN Facebook page, the CDN Twitter feed, and the Delaware Chapter of the JDRF. All interviews were coded by two researchers with coding discrepancies resolved using an iterative process. Researchers used a thematic analysis to analyze the data and develop categories. Interviews were conducted and recorded via ZOOM video conferencing from July 2019 to September 2019.

**Results:** Results represent data from 16 interviews comprised of 15 (94%) mothers and 1 father. Thematic analysis resulted in the emergence of three themes: managing parental concerns in the transition to college with T1DM, changes in the parental role in T1DM management during the first two years of college, and identifying sources of parental support during the first two years of college. Parents identified several facilitators and barriers including the EYA's ability to manage T1DM at college, communication with the EYA, and the availability of support for parents.

**Conclusions:** Parents experience several barriers and facilitators during their EYA's transition to college with T1DM. Supporting the needs of parents and EYAs during

this time may serve to reduce diabetes-related complications for EYAs and increase overall quality of life for both members of the dyad.

## **Introduction**

Nearly 2 million students and their families will transition to college in fall 2020 (National Center for Educational Statistics, 2019). The transition to college heralds the beginning of a period of significant change for parents as their emerging young adults (EYA) begin to form and establish their own separate identities. This individuation requires the parents and EYA to renegotiate their relationship as the EYA moves in and out of the family system during the college years (McGoldrick, Preto, & Carter, 2015). Parents who are unable to individuate from their EYA during this time will be unable to successfully move on to the next stage of life or support their EYA through their own personal transition (Karp & Holmstrom, 2004; McGoldrick et al., 2015). This process of renegotiation is more complex in the presence of a chronic condition such as type 1 diabetes mellitus (T1DM).

T1DM is a chronic condition in which the pancreas produces little to no insulin, a hormone necessary to regulate blood glucose levels. T1DM requires a complex system of management, including blood glucose monitoring, insulin administration and carbohydrate counting, to maintain desired blood glucose levels (hemoglobin A1c goal of <7% [58 mmol/mol] in adults; American Diabetes Association [ADA], 2019). Often diagnosed in childhood, the primary responsibility for T1DM management defaults to parents. As the transition to college approaches, the level of support provided by parents should gradually decrease as EYA's assume increased levels of responsibility for T1DM management.

Research has shown that EYA's are at increased risk for T1DM-related complications with >80% of young adults routinely failing to meet recommendations for glycemic control (Monaghan, King, Alvarez, Cogen, & Wang, 2016). The risk for deterioration in glycemic control continues through age 25 (Clements et al., 2016); therefore, the need to establish appropriate T1DM management is imperative as the EYA transitions to college. Diabetes management responsibility must shift from the parent to the EYA in an organized manner, supported by the diabetes healthcare team (Palladino et al., 2013; Smart, Annan, Bruno, Higgins, & Acerini, 2014); however, there is limited guidance regarding what aspects of T1DM management should be transitioned to EYA's and when the transition should occur.

Research has shown that EYAs with continued parental involvement in their care have better diabetes-related outcomes (Carcone, Ellis & Naar-King, 2012; Hanna, Dashiff, Stump, & Weaver, 2013; Lekes, Gingras, Philippe, Koestner, & Fang, 2010; Moreira & Canavarro, 2016; Schultz & Smaldone, 2017); however, the level of parental involvement is unclear and there is limited research focused on the challenges that parents of EYAs with T1DM encounter. There is no specific guidance for providers from the ADA (2019) regarding the role of the parent during this time. Complicating this is the Health Insurance Portability and Accountability Act (HIPAA) which forbids healthcare providers from sharing information regarding the EYA's health status after they reach the age of 18 without consent. Lack of information regarding transition from providers may lead to uncertainty regarding appropriate levels of parental involvement and support of the EYA with T1DM during this time.

Research has shown that parents who are concerned about their EYA's ability to manage their diabetes care experience increased levels of distress, which may

negatively impact the transition process, including the ability to let go (Castensøe-Seidenfaden et al., 2017; Hessler, Fisher, Polonsky, & Johnson, 2016; Law, Walsh, Queralt, & Nouwen, 2013). Parental resistance to let go may inadvertently create a sense of quasi-dependence, leading parents to have concerns about their EYA's ability to manage their T1DM while at college (Castensøe-Seidenfaden et al., 2017; Ersig, Tsalikian, Coffey, & Williams, 2016; Law et al., 2013).

Much of the literature exploring the phenomenon of transition with T1DM focuses on the individual with T1DM as they transition from pediatric to adult diabetes care providers (Agarwal et al., 2016; Lotstein et al., 2013; Majumder, Cogen & Monaghan, 2017; Palladino et al., 2013; Smart, Annan, Bruno, Higgins, & Acerini, 2014), yet there is a paucity of information regarding the experience of parents in the process. There is little to no literature that explores the concerns of parents once their EYA with T1DM has been in college for 1-2 years, nor is there literature that indicates if the concerns prior to the transition to college with T1DM are the same or different as those experienced during and after the transition. Given this complexity, the purpose of this study is to identify facilitators and barriers that parents faced as their EYA with T1DM completed the transition to college. Findings will serve to inform the development of family-centered interventions designed to support families and improve diabetes-related outcomes.

## **Methods**

### **Research Design**

A descriptive, qualitative study was conducted to gain a better understanding of the parental experience of EYAs with T1DM who have completed their freshman or

sophomore year of college. Using semi-structured interviews, the research team employed an inductive thematic approach to identify themes that led to a better understanding of this phenomenon and an in-depth description of the experience (Braun & Clarke, 2006; Kim, Sefcik, & Bradway, 2017; Sandelowski, 2000). The University of Delaware Institutional Review Board (IRB) approved this study (Appendix D).

### **Sample**

A purposeful sample of 16 participants were enrolled in this study. An IRB-approved flyer featuring a link to a screening tool was posted in local endocrinology clinics as well as on the College Diabetes Network (CDN) Parent Facebook page, the CDN Facebook page and Twitter feed, and was shared with a contact at the Delaware Chapter of the JDRF. Recruitment and interviews took place between July 2019 and September 2019. All parents were required to be biological or adoptive parents, step-parents, legal guardians, or parent figures of EYAs with T1DM who were 18-21 years of age. EYAs were required to be the first in the family with T1DM to attend college; have completed their freshman or sophomore year in college; and currently enrolled in college. Parents were required to speak and read English and have access to a computer with video chat capability. Thirty-two parents consented to participate in the study and completed the demographic/T1DM questionnaire and sixteen parents completed the interview.

### **Data Collection**

Interested parents completed the screening tool to determine eligibility to participate in this study. Once the eligibility survey was complete, participants

received the link to the informed consent, via REDCap [Research Electronic Data Capture] (Harris et al., 2009). After consent was received, parents received the link to the demographic and T1DM-related information survey. Once the survey was complete the participant was contacted to set up a mutually agreeable time for the video-conference interview.

Data were collected through semi-structured interviews conducted by the first author via a remote conference service. Open-ended questions (Table 5), guided by the Revised Self- and Family Management Framework (Grey et al., 2014), served to identify barriers and facilitators to the transition process, indicating what parents found to be helpful and not helpful in the transition. Probing and follow-up questions were asked; interviews lasted approximately one hour. Participants were able to speak freely beyond the interview questions. After all interviews were complete, participants were compensated by entering their name into a drawing for one of four Amazon gift cards worth \$25 each.

### **Data Management**

Interviews were conducted and recorded in a private office via ZOOM video conferencing technology at a prearranged time and were transcribed verbatim by a professional transcriptionist. Only the audio transcripts were shared with the transcriptionist. Transcripts and video interviews were cross-checked and reviewed for accuracy. Confidentiality was maintained by using aggregate coding during data analysis and removing all names and identifiers in the manuscript.

Table 5 Semi-structured interview questions

Walk me through the process of sending your son or daughter off to college.
How did type 1 diabetes impact that process?
What did you (as the parent) find to be particularly helpful in the transition process?
Think back to your emotional state as you were preparing for the transition and pending separation. What support did you receive?
What information did you receive from your son or daughter's diabetes care provider about the transition to college?
Walk me through your role in your son or daughter's diabetes management over the past few years.
Walk me through what diabetes management looks like now.
Tell me how you anticipate next year going.
With regard to the transition to college, what would you do differently, knowing what you know now?
Looking back, what additional information, support, or other resources might have made the transition easier as a parent?
Is there anything else you think I should know?

### Data Analysis

The first and second author read the verbatim interview transcripts of the parent independently and conducted separate systematic thematic analyses. Parent responses were carefully read to identify emergent ideas and initial thoughts prior to beginning the coding process (Creswell & Poth, 2018). These emergent ideas and key concepts were grouped during the initial reading to aid in the identification of the initial categories as well as to create a digital audit trail that will serve as the foundation of the validation strategy (Creswell & Poth, 2018). Once the initial interpretation of the data was complete, an inductive coding system was applied to

identify themes and patterns that emerged in the narrative data (Creswell & Poth, 2018).

The first and second author read the transcripts a second time to reveal any additional information necessary to further validate the research as well as ensure that the themes are appropriately aligned with the study findings to create a final codebook (Braun & Clarke, 2006). The final code book included eight initial categories and resulted in three major themes. Approximately 85% intercoder agreement regarding codes and themes for text segments was established by using an iterative process of re-coding, re-reading, and re-analyzing transcripts to yield final themes and subsequent sub themes (Creswell & Poth, 2018). During the final phase of thematic analysis, the first and second author chose participant examples for each theme as it related to the study purpose.

### **Trustworthiness**

Findings were triangulated and validated by locating evidence of qualitative codes in the T1DM information survey. Transferability was achieved by using a detailed research process and a purposeful sample of parents of EYAs with T1DM who have completed their freshman or sophomore year of college. The original transcripts were compared to ensure that clear connections to the data are evident (Lincoln & Guba, 1985). An experienced qualitative researcher served as an auditor to examine the process of inquiry from beginning to end to establish dependability and confirmability simultaneously (Lincoln & Guba, 1985). Confirmability was evidenced when the findings, interpretations, and recommendations were supported by the interview data (Lincoln & Guba, 1985). The consolidated criteria for reporting

qualitative research (COREQ) checklist was used to report the methods, analysis, and study results (Tong, Sainsbury, & Craig, 2007).

### **Theoretical Framework**

The Revised Self- and Family Management Framework (Grey, Schulman-Green, Knafl, & Reynolds, 2015) aids in the identification of facilitators and barriers that may influence self-and family management processes, noting both proximal and distal outcomes (Grey et al., 2014). Facilitators and barriers include personal/lifestyle, health status, resources, environmental, and health care system factors that may be associated with the self-management of chronic conditions (Grey et al., 2014).

## **Results**

### **Sample characteristics**

Study participants (n = 16) were white, non-Hispanic, married, biological parents of EYAs with T1DM (see Table 6). Household size ranged from three to six people, including parents. EYAs were the first in the family with T1DM to attend college and were between 18 and 21 years of age (see Table 7). EYAs were diagnosed with T1DM between 3 and 15 years of age with a mean of 9.83 ( $\pm 3.93$ ) and had an average hemoglobin A1c of  $8.10 \pm 2.31$  %.

### **Themes**

A thematic analysis of the qualitative data resulted in 3 major themes and subthemes highlighting potential barriers and facilitators experienced by parents during the transition process. Themes include: 1) managing parental concerns in the

transition to college with T1DM; 2) changes in the parental role in T1DM management during the first two years of college; and (3) identifying sources of lack of support during the first two years of college.

Table 6 Sociodemographic and diabetes-related characteristics of study participants (n=16).

Sample Characteristic	n (%)
Participants	
Mothers	15(94%)
Fathers	1(6%)
Education Level	
High School	1(6%)
Associate's or bachelor's degree	8(50%)
Advanced degree	7(44%)
Involvement with diabetes management	
Waking up for lows	3(19%)
Site changes	1(6%)
Monitor CGM	5(26%)
Supply orders	11(58%)
Insurance	13(81%)
Making appointments	8(50%)
Transition meeting with provider	
Yes	5(31%)
No	7(44%)
Unsure/No response	4(25%)
Transition meeting with diabetes organization	
Yes	5(31%)
No	9(56%)
No response	2(13%)

Note. <sup>a</sup>CGM=Continuous glucose monitor.

Table 7 Sociodemographic and diabetes-related characteristics of emerging young adults with type 1 diabetes who have completed their first or second year at college (n=16)

Sample Characteristic	M±SD/ N (%)
Age when T1DM was diagnosed	9.83 ±3.93
Hemoglobin A1c <sup>a</sup>	8.10± 2.31
Gender	
Male	6(37%)
Female	10(63%)
Insulin management	
Pump	
Yes	15(94%)
No	1(6%)
CGM <sup>b</sup>	
Yes	14(88%)
No	2(12%)
Shared CGM	
Yes	8(50%)
No	8(50%)
Doctor's visits while at college	
0	1(6%)
1-2	5(31%)
3-4	3(19%)
5-6	0
7-8	3(19%)
9 or more	2(12%)
No response	2(12%)
Hospitalizations while at college	
0	0
1-2	1(6%)
3-4	0
5-6	1(6%)
7 or more	0
No response	14(88%)

Table 7 continued

Accommodations while at college	
Schedule modifications	2(12%)
Extra testing time	6(38%)
Refrigerator in room	3(19%)
Air conditioning	3(19%)
Car on campus	1(6%)
Food and drink in class	10(63%)
Come to class late	1(6%)
Other <sup>c</sup>	5(31%)

*Note.* <sup>a</sup>Unit: %. <sup>b</sup>CGM=Continuous glucose monitor. <sup>c</sup>Allowed to have phone in class; Extra class absences if approved by professor, clock stopping during testing for breaks due to diabetic needs (feels high, low, needs to test, etc...), tests in separate location; single room.

### **Theme 1: Managing Parental Concerns in the Transition to College with T1DM**

Parents of EYA's with T1DM perceived that their concerns were above and beyond those of parents of EYA's without T1DM. One mother noted. "Normal things that parents are worrying about, drinking, bullying, whatever, getting in the car and driving, it's compounded even 10 times fold". Parents reported that fear of the unknown amplified these concerns which led to "an underlying level of anxiety". While most EYAs in this study sample attended college within a three-hour drive from home, parents reported that closer distance helped with the transition, yet they did not feel obligated to "drop everything and rush" to their EYA when they had an issue with diabetes management at college. Despite this, parents remained concerned for both their EYA's health and safety and their ability to manage their T1DM while at college.

Concern about EYA's health and safety at college.

The transition to college brought to light new concerns related to the college environment. Prior to the transition to college, many parents reported that their EYAs were still reliant on parental intervention for low blood sugar during the middle of the

night. As EYA's completed their first or second year of college, parents reported that this continued to be an issue, leading to concerns about nocturnal hypoglycemia, particularly since they were no longer "just down the hall". Parents expressed increased levels of concern about the possibility that their EYA would suffer from low blood glucose levels and not wake up in the morning. Concern about the risk of nocturnal hypoglycemia is unique to T1DM and vastly outweighed other concerns, creating a potential personal/lifestyle and health status barrier to parental transition. One mother stated, "I think... most parents you'll find are most concerned with low blood sugars in the middle of the night."

Concerns about nocturnal hypoglycemia were compounded by increased access to alcohol on college campuses. Parents frequently reported observing low blood glucose continuous glucose monitor (CGM) readings during periods of alcohol consumption. While alcohol consumption in college is a potential concern for many parents, this concern is heightened for parents of EYAs with T1DM as the effects of alcohol may lead to significant issues with blood glucose control as alcohol consumption is associated with increased insulin resistance, difficulty with glycemic control, poor diabetes self-care behaviors, increased risk of severe hypoglycemia, as well as diabetic ketoacidosis (DKA), presenting a potential health status barrier to parental transition; this prompted one mother to say "when his sugar is crazy, because I know that there's alcohol involved, so then I'm more stressed out when I'm getting low alerts." This concern was echoed by several parents with one mother stating, "Alcohol, I can tell you, has been the biggest difficult transition to college."

Parents also expressed concerns about the potential for diabetes burnout. Many parents managed their EYA's T1DM when they returned home for the weekend to

“give them a break”, resulting in a continued state of quasi-dependence that may affect their EYA’s blood glucose control in the future. One parent noted, “In the back of my mind is being a real concern that she’d get up there and just say forget it. Diabetes burnout, like it’s a real thing”.

Concern about EYA’s ability to manage T1DM at college.

Parents reported actively working to find the balance between letting go and holding on to both their EYA and the management of the EYA’s T1DM, potentially serving as a personal/lifestyle barrier and/or facilitator to the parental transition. While some parents felt confident in their EYA’s ability to self-manage their T1DM prior to leaving for college, others felt that their EYA could manage their condition better by monitoring their blood glucose levels more closely to maintain levels in the desired range more frequently. One mother reflected on the first year of school by stating, “I resented the fact that she didn't take her disease as seriously as I did or I wanted her to.”

Trusting their EYA and understanding that mistakes will be made may be seen as a personal/lifestyle facilitator to the parental transition and helped parents put the transition into perspective. A parent stated, “If she's not able to handle it herself, anything about it, she can call us and we can talk through it, but generally speaking, she handles everything at this point.” Another parent noted:

You’ve got to let them make mistakes, I guess. I mean, you’re not doing them any favors by doing everything for them, and they will, just like with anything. It’s a good growing time to know they’re able, but it’s nice to watch them come back and see how much they’ve grown and confidence that they can do it.

As EYAs approached the time of transition, parents indicated that EYA’s were independent in T1DM management and the parent typically no longer attended

diabetes care provider appointments with them. Parents indicated that while they would not do anything different to prepare themselves for their EYA's transition to college, they would likely just have attempted to push their EYA to be more independent in their T1DM management earlier in the transition process. Parents who perceived their EYAs to be independent in T1DM management at the time of departure for college reported that the transition experience was "freeing" in that their relationship no longer centers on diabetes, which appeared to be a personal/lifestyle facilitator to the parental transition. One mother noted, "You want them to be able to be independent in whatever it is you're teaching them to be able to do it on their own, so I feel good about that."

## **Theme 2: Navigating Changes in the Parental Role in T1DM Management During the First Two Years of College**

As EYAs begin to transition away from the home, the parental role evolves from the parent of an adolescent to the parent of an EYA. This role change is more complicated in the presence of T1DM. Parents of EYAs reported their role in T1DM management changed from being the primary manager of T1DM to that of a supporting role now that their child is in college. One father said, "When you're a parent, you identify with that role and taking care of your Type 1 diabetic...and it's hard to give up that role." Decreasing communication from the EYA as well as challenges navigating the nuances of campus life led parents to reevaluate their expectations. One mother stated:

It's a little bit hard when you get kicked out of that job, which is what's happening. I mean that's a good thing, but it makes me feel a little bit less in control and I don't necessarily like that.

Parents expressed concerns about being torn between actively managing care from a distance and being in “emergency response mode” or only providing guidance as necessary. One mother told her EYA:

“You have to make these decisions for yourself.” So, I kind of let that go last year [freshman year]. I do like to have control of things, but I know that that's not something I can do for her.

Prior to the transition to college, parents universally reported working to promote independence by encouraging their child to be responsible for their own diabetes care; however, parents noted that they retained some level of involvement with their EYA’s diabetes management while away at college. This appeared to serve as a personal/lifestyle facilitator the transition by allowing parents to maintain some sense of control over the process. Nearly all parents ordered diabetes supplies and managed health insurance issues, while some parents packed and organized their EYA’s diabetes supplies for college. Parents reported maintaining diabetes supplies at home and either driving or shipping them to their EYA rather than having them delivered directly to campus related to issues with campus mail services.

The impact of technology.

The structure of the college schedule and parental access to diabetes-related technology served as an environmental barrier for parents related to challenges in communicating with their EYA regarding their T1DM. Several parents reported requesting information regarding their EYA’s blood glucose levels on a daily basis either via text message or continuous glucose monitor (CGM). Of parents who had access to their EYA’s CGM data (n=8), over half continued to monitor their EYA’s CGM data on their phone after the transition to college was complete. Parents

frequently reported seeing their EYA's blood glucose levels decreasing rapidly on their CGM and being unable to connect with their EYA. One mother said:

We monitor it from afar. We watch it on our cell phones. When he's double arrow down, I mean we've caught him in double arrows down, which means he's dropping about, I want to say, ten points a minute when you're double arrows down. It's a crazy number, and just you can't even believe it's happening.

This prompted panicked parents to contact campus security or a resident assistant to attempt to make contact with their EYA. "I am still worried that he could end up dying, from high or low blood sugar. Just the bottom line is I feel like that's always in the back of my mind." This resulted in parents desiring more information about their EYA's T1DM management, potentially serving as a barrier to the parental transition, with one mother saying, "I still find myself peeking at the CGM, his blood sugar numbers while I'm at home."

Conversely, some parents indicated that they intentionally moved away from communicating with their EYA about T1DM, which may be a personal/lifestyle facilitator to the parental transition. One mother indicated that she broadened her monitoring parameters on her son's CGM, stating "When he went to college, I had to widen that, because I can't be bothering him for every little thing...definitely backing off on the micromanaging kind of thing". Another mother stated, "It was too much information for me and for me not to be there to do something about it."

### **Theme 3: Identifying Sources of Parental Support During the First Two Years of College**

Parents found support from the Internet and social media to inform the transition process, which served as a personal/lifestyle facilitator to the transition. One mother said, "I think, honestly now, this day and age with a computer and Facebook

groups, I mean you can throw anything out there, and a parent's been through it, done it, can assist you any way." Non-profit diabetes organizations such as CDN and JDRF provided parents with much desired information and connections to other parents, with several parents indicating that their EYA's involvement in their on-campus CDN organization was of comfort to them.

Lack of support was found to be a significant component in the transition process for parents. In addition to support found from online sources, prior to the transition, parents reported receiving support from a variety of sources including family and friends as well as their EYA's school nurse. After the transition parents reported receiving limited support from both diabetes care provider as well as colleges/universities.

Lack of support from diabetes care provider.

Parents indicated generally positive relationships with diabetes care providers until their EYA reached the age of 18, when federal privacy laws restrict information to parents, creating a potential health care barrier to the parental transition. While some parents indicated they attended diabetes transition groups offered by their diabetes care providers in anticipation of the college transition, parents indicated that these meetings left them feeling "not very" to "a little prepared". Support received was typically in pamphlet format that was directed at EYAs with a focus on accommodations at college. Several parents indicated that they received little to no support at all from their EYA's diabetes care providers, particularly if their EYA had transferred from a pediatric to an adult diabetes care provider. This lack of professional support made parents feel "alone" in the transition process.

Lack of support from the college/university.

Parents reported a general lack of connection to the college or university. Parents indicated that they attempted to involve themselves in their EYA's health care and accommodation plans at college, but due to federal privacy laws they were denied access to that information. This left parents feeling "shut-out" of their EYA's lives and appeared to be an environmental barrier to the transition process. One mother noted, "I would have loved to be able to call somebody or know somebody at the college she was going to, that would be like the adult she could turn to." Parents noted a lack of healthcare options on or near campus, which led to uncertainty regarding their EYA's health and safety. Parents also indicated that making a connection with their EYA's roommate was significant. Knowing that someone was there to support their EYA in the case of an emergency put parents' minds at ease. One mother stated:

Her roommate ...just connected so well that the first time they had her out they were like, hey, can you check us out, like teach us about your disease? They were so good about it. ...her roommate took that on to, to want to help, which I think was comforting for me.

## **Discussion**

The purpose of this study was to gain a deeper understanding of the barriers and facilitators experienced by parents of EYAs with T1DM who have completed their freshman or sophomore year of college. Identified themes serve to highlight a variety of factors that affect parents during the transition process. Similar to research conducted by Ness et al. (2018), this study found that parents have unique needs as their EYA with T1DM transitions to college. While all parents worry about their EYA during the college years, parents of EYA's with T1DM are primarily concerned with short-and long-term complications of T1DM including hypo- and hyperglycemia, Literature indicates that prior to the transition to college, parents have concerns about

their EYA's safety at college, including worries about nocturnal hypoglycemia and alcohol consumption (Castensøe-Seidenfaden et al., 2017; Ersig, Tsalikian, Coffey, & Williams, 2016; , Hanna, Weaver, Stump, Fortenberry, & Dimeglio; 2014; Law et al., 2013; Ness et al., 2018). In this study of EYAs with T1DM who have completed their freshman or sophomore year of college, nearly all participants continued to express these major concerns, which may create a barrier to the parental transition due to increased distress.

Research has demonstrated that families serve as both a facilitator and barrier to the process of transitioning EYAs to college (Karp, Holmstrom, & Gray, 2004; Kloep & Hendry, 2010). Parents indicated that their changing role in their EYA's diabetes management lead to challenges as they worked to balance holding on and letting go, not only of their EYA but also of their role in diabetes management. This is new to the literature as no studies have focused on parents and letting go. Parents who reported promoting autonomy from an early age or early into their EYA's diagnosis indicated that they felt positive about their EYA's ability to self-manage, which appeared to serve as a facilitator to the transition; however, some parents felt that their EYA could be managing their T1DM better, leading to increased distress resulting in a potential barrier to transition.

As in previous research, facilitators in the parental transition may include an EYA's high level of ability and motivation to self-manage diabetes while at school as well as the willingness of the parent to trust their EYA to take control (Ersig, 2019; Ness et al., 2018; Sullivan-Bolyai et al., 2014). While existing research indicates that parents play a significant role in the transition of diabetes management (Ersig et al., 2016; Hanna et al., 2013; Majumder et al., 2017), this is the first study to focus

exclusively on the parent experience during the transition to college. Facilitators to the parental transition include trusting that their EYA will do their best to manage their T1DM at college and understanding that mistakes in T1DM management are likely. These findings are similar to research that indicated that parent diabetes-related distress decreased as EYAs assume diabetes management responsibility (Castensøe-Seidenfaden et al., 2017; Ersig et al., 2016; Hessler et al., 2016; Ness et al., 2018).

Parents admitted to challenges with wanting to control their EYA's diabetes management from afar. In an attempt to maintain control over T1DM management, some parents report relying on CGM data to monitor their EYA's blood glucose levels. While parents determined that this type of oversight was negatively impacting their relationship with their child, others insisted that their EYA share their blood glucose levels on a daily basis. For parents of EYAs with a CGM, this connection served as a facilitator to relinquishing control of T1DM management; however, for parents of EYAs without a CGM or those who refused to share blood glucose information, this ultimately proved to be a barrier to the transition.

Parents also focused on organization and management of supplies as a means of maintaining some control over the transition, which serves as a facilitator to the parental transition. While parents typically continue to manage insurance issues and supplies during and after the college transition, some parents continue to serve as a backup responder for diabetic emergencies such as hypoglycemia. This ambiguous role seemed to create a barrier to the parental transition as it created uncertainty for parents. These findings are similar to research that demonstrated that parents continue to serve as partners in the continued management of T1DM throughout the college transition (Castensøe-Seidenfaden et al., 2017; Law et al., 2013; Walsh Donnell, &

Hara, 2018); however, this specificity to the role of parents during the transition to college is new to the literature. Distance from home and access to diabetes-related technology, such as a CGM, appeared to make managing from a distance more feasible and gave parents comfort during the first years at college.

Parental ability to transition may also be positively or negatively impacted by the type of support received prior to and during the college transition. Support received from Facebook groups and organizations such as JDRF and CDN appeared to be a facilitator in the parental transition. Involvement with JDRF and CDN was seen as a positive experience for both parents and EYAs. As parents prepared to send their EYA with T1DM to college, parents reported receiving support from friends and family but reported varying levels of involvement with their EYA's diabetes care provider. The transition to college may be made more complicated by the fact that college-bound EYAs usually reach the age of 18 prior to the transition to college and are recognized as an independent agent in the health care setting by HIPAA. After the age of 18, health care providers are not permitted to share information about the EYA with parents without obtaining consent and tend to leave parents out of the transition planning process. This is a significant barrier to the parental transition.

Consistent with other literature, parents would like to receive more information about how to plan for the college transition as well as specific resources regarding T1DM management in the college setting (Ersig, 2019; Sullivan-Bolyai et al., 2014). The lack of support from providers created a barrier to the parental transition. Parents reported that attendance at transition meetings offered by diabetes care providers and non-profit diabetes organizations did not enhance parental preparedness for the college transition. This is in contrast to literature which indicated that parents would be

interested in receiving support in the group setting (Ness et al., 2018). Nearly all parents reported that there was a lack of information and minimal support from diabetes care providers. Lack of guidance from providers regarding the role of the parent created a barrier to the transition.

As in previous research, parents indicated their desire to maintain contact with a responsible adult on campus, but due to federal privacy laws this is challenging (Ness et al., 2018). Being able to communicate with their EYA's roommates or friends during an emergency situation appeared to make this lack of connection less of a barrier. Parents expressed concerns regarding the healthcare options available on or near campus. This is significant as research has found that EYAs who move away for college may have difficulty obtaining necessary support from HCPs on or near campus; however, parents and youth both report that coming home for T1DM management is a barrier (Walsh et al., 2018).

### **Potential Limitations**

Potential limitations of this study include a small, non-diverse sample, which may limit applicability to other populations. Participants were primarily mothers (n=15), married, white, non-Hispanic parents. Interviews were not conducted face to face limiting interaction with participants; however, using ZOOM video conferencing technology allowed for real time video capability and the ability to reach beyond a local area. This study does not consider the varying demographic and psychosocial factors, such as family size, socioeconomic status, and comorbidities that may impact T1DM during the transition to college; therefore, there are likely other variables that impact families during this time.

## **Recommendations for Research and Clinical Practice**

More research is needed to identify the available and necessary educational and emotional support for parents as they transition their EYA with T1DM to college or out of the home to live independently. A national study focused on the types and amount of support needed by parents during the college transition can drive the initiation of family-centered interventions designed to increase parental willingness to let go and promote autonomy for EYAs.

Parents experience many barriers and facilitators during their EYA's transition to college with T1DM. Clinicians working collaboratively with college-bound EYAs with T1DM and their parents should consider the following:

- Assess parental involvement in daily diabetes management to determine the EYA's level of autonomy, specifically management of nocturnal hypoglycemia to determine potential education needs for both parents and EYA's to promote independence in T1DM management.
- Include parents, with EYA consent, in transition planning conversations to proactively address parent concerns.
- Work with parents individually to provide additional resources and support that are tailored to the parent experience with a focus on potential barriers, such as lack of a specific contact person at school, to help reduce parent distress during the first two years of college.
- Provide education regarding alcohol consumption and its effects on T1DM to ensure that parents and their EYAs have an understanding of how alcohol will affect blood glucose.

## **Conclusion**

While the majority of research about transition in T1DM focuses on the EYA and the transition from pediatric to adult diabetes care providers, this is the first study to focus on the parental experience during their EYA's first years at college with

T1DM. This research indicates that while the transition to adult care provider may occur via a set of planned behavioral interventions, the emotional and educational needs of parents are not being addressed. Parents play an important role in the transition to college as EYAs are still reliant on parents for varying levels of support ranging from handling health insurance and supply issues to monitoring blood glucose via CGM. Identifying potential barriers and facilitators for parents during the college transition process will inform the development of interventions designed to support families as they move to the next stage of life with T1DM. Supporting the needs of parents and EYAs during this time may serve to reduce diabetes-related complications for EYAs and increase overall quality of life for both members of the dyad.

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## CONCLUSIONS AND RECOMMENDATIONS

### Overview of Background and Specific Aims

An emerging young adult's (EYA) transition to college is an exciting and challenging time for parents. This transition requires parents to adapt to their own set of challenges including normative life events as well as renegotiate relationships and responsibilities within the family system (American Psychological Association, 2014; McGoldrick, Preto, & Carter, 2015; Napolitano et al., 2017). During the transition to college many EYAs remain reliant on parents for economic and financial support, resulting in a state of quasi-independence, potentially leading to parental role confusion and difficulty letting go (Karp, Holmstrom, & Gray, 2004; Sandberg-Thoma, Snyder, & Jang, 2015; Settersten & Ray, 2010). Families who are not able to adapt to these changes during the transition period are at risk for entrenchment, subverting their healthy development along the lifespan (McGoldrick et al., 2015). This transition is increasingly complicated when coupled with the presence of a chronic condition, such as type 1 diabetes mellitus (T1DM) in the EYA (Akre & Suris, 2014; Livesey & Rostain, 2017).

While research has identified EYA concerns during the transition to college with T1DM, there is a dearth in the literature related to the parents of EYAs with T1DM and their transition to college. The current research explored parent perceptions before the transition to college occurred and after the first year or two the EYA was in college and accomplished the following aims: 1) systematically review the literature to identify the state of the science about facilitators and/or barriers impacting parents as

they transition their EYA with T1DM to college (chapter two); 2) explore the experience of parents of high school students with T1DM as they prepared for the college transition (chapter three); and 3) identify barriers and facilitators faced by parents as their EYA with T1DM completed their freshman or sophomore year of college (chapter four). This chapter summarizes the study findings, outlines the barriers and facilitators experienced by parents both before and after the college transition, and highlights potential clinical implications as well as opportunities for additional research to provide a beginning knowledge base regarding the parental transition during their EYA's transition to college with T1DM.

### **Summary of Findings**

#### **Parental Concerns in the Transition to College with T1DM**

Parents both before (chapter 3) and after the college transition (chapter 4) shared similar concerns including their EYA's ability to manage their T1DM while at college; the potential for complications of poor blood glucose control, such as nocturnal hypoglycemia; and involvement in risky behaviors, such as alcohol consumption. Parents before the transition (chapter 3) were optimistic that their EYA could manage their T1DM at college independently; however, parents after the college transition (chapter 4) found that their EYA remained partially dependent on their parents for T1DM management, particularly during the overnight hours.

Parents of high school seniors (chapter 3) and college freshmen/sophomores (chapter 4) indicated that despite promoting independence, they remained concerned about their EYA's ability to manage their T1DM at college. Parents after the college transition (chapter 4) indicated that they should have done more to promote

independence prior to the transition to college and felt that their EYA would have been in better control of their T1DM, including blood glucose management, at school. These concerns were perceived to be a barrier to the parental transition.

Similar to the results found in study one (chapter 3) and study two (chapter 4), the integrative review (chapter 2) indicated that parents have ongoing concerns about EYA blood glucose management issues, including high hemoglobin A1c; changing dynamics in the relationship with their EYA, including disagreements about responsibility for T1DM management; and concerns about the availability of a healthcare provider with knowledge of diabetes near or on campus. Contrary to the literature review (chapter 2), parents did not restrict college choice to remain close to healthcare providers, as distance from home was not a concern for parents of EYAs who had completed the transition to college (chapter 4). While the literature review (chapter 2) indicated that parents experience distress related to personal issues in their own transition as well as increased concern about EYA distress, parents both before (chapter 3) and after the college transition (chapter 4) did not express these concerns.

Similar to the results from chapters 3 and 4, literature that has focused on the transition to college with T1DM suggests that EYAs may struggle to manage academics, sleep, nutrition and physical activity in conjunction with T1DM management (Palladino et al., 2013; Saylor & Calamaro, 2016; Smart, Annan, Bruno, Higgins, & Acerini, 2014). As responsibility for T1DM management transfers to the EYA, blood glucose monitoring decreases, increasing the risk for diabetes-related complications (Hessler, Fisher, Polonksy, & Johnson, 2016). These concerns were valid as parents before (chapter 3) and after the transition (chapter 4) indicated that alcohol use is a major concern. Parents before the college transition (chapter 3)

assumed that their EYA would be independent in T1DM management while at college; however, parents of EYAs who had transitioned to college (chapter 4) reported that this is not the case. This research found that despite years of promoting independence, EYAs remain somewhat dependent on parents for T1DM management, leading parents to worry about their EYA's ability to manage in the college setting. This indicates that the preparation for the departure to college may require unique transition guidance. This is significant as this may indicate the need for additional research on the education needs of both parents and EYAs during the transition to college.

### **Parental Role in the Transition to College with T1DM**

Parents experienced a sense of role confusion as they attempted to discern whether they should be serving in a consulting role or actively managing their EYA's T1DM from a distance. Parents both before (chapter 3) and after the college transition (chapter 4) indicated that they continued to serve as a "safety net" for T1DM management and that their EYA was still reliant on them for overnight T1DM management. Parents of college students (chapter 4) indicated that they served in a consulting role and as a back-up responder for T1DM emergencies. Parents also had difficulty delineating their role in T1DM management when EYAs returned home from college; parents of college students (chapter 4) reported managing overnight care for their EYA when they came home for the weekend or on breaks from school. This inadvertently enhanced the sense of quasi-independence, further adding to the role confusion that parents experience during this time.

Parents before (chapter 3) and after the college transition (chapter 4) report difficulty finding a balance between letting go and holding on to both their EYA as

well as the T1DM management. Parents of high school seniors (chapter 3) report looking forward to a time when their relationship with their EYA did not focus solely on communication about T1DM management. Parents of EYAs who completed the transition (chapter 4) to college echoed this feeling reporting that they were also looking forward to a time when their relationship with their EYA was more than T1DM; however, parents reported the desire to maintain at least some control over T1DM management. Parents of students who had completed the transition to college (chapter 4) reported that they continued to manage their EYA's T1DM supplies as well as insurance issues. This sense of control served as a facilitator to the parental transition.

The review of the literature (chapter 2) indicated that changes in the dyadic relationship related to the EYA's transition to college left parents feeling unsure about their current role in their EYA's T1DM management. The EYA's transition to college takes place concurrently with the parental transition to the next stage of parenting and may lead to instability, which may leave the family vulnerable to increased stress and ineffective coping (Akre & Suris, 2014; McGoldrick et al., 2015). Compounding this issue is literature that indicates that parents feel pressured to retain at least some responsibility for T1DM tasks (Sullivan-Bolyai et al., 2014), despite the need to promote independence. This dichotomy is likely related to literature that states that high levels of parental support are associated with a higher level of shared responsibility, leading to better psychosocial health for both parents and EYAs (Strand, Brostrom, & Haugstvedt, 2018; Sullivan-Bolyai et al., 2014); however, parents in study two (chapter 4) revealed that they were unsure of their role in their

EYA's T1DM management at that time, potentially leading to confusion regarding their current role.

As EYAs with T1DM mature, responsibility for T1DM management must shift from parents to EYAs; however, evolving roles in the parent/EYA dyad and increased levels of distress related to the transition may lead parents to struggle with relinquishing control of diabetes care to their child (Hanna, Dashiff, Stump, & Weaver, 2013; Moreira & Canavarro, 2016; Ness, Saylor, & Selekman, 2018; Schultz & Smaldone, 2017). This heightened level of concern may lead parents to struggle with relinquishing control due to concerns about their EYA's ability to navigate college life as well as fear of the unknown as their EYA transitions to life on a college campus (Carcone, Ellis, & Naar-King, 2012; Hanna, Weaver, Stump, Guthrie, & Oruche, 2013; Schultz & Smaldone, 2017).

The concept of "letting go" is new to the diabetes literature and deserves further exploration. This research indicates that parents who do not feel that their EYA is ready to independently manage their T1DM in the college setting are reluctant to 'let go' for fear of the negative consequences associated with poor glycemic control. This is significant as providers who work with families of EYAs with T1DM may not be aware of the impact of parenting styles and the importance of ensuring that parents are ready to let go.

### **Diabetes Management Independence in the Transition to College**

Parents before (chapter 3) and after the transition to college (chapter 4) indicated that the promotion of independence in T1DM management was a high

priority. Mothers of high school seniors (chapter 3) reported that they did not have a formal plan in place to transition all aspects of T1DM management to their EYA, yet they were aware that their EYA should be primarily responsible for their care once they transitioned to college. Mothers of high school seniors (chapter 3) and parents after the college transition (chapter 4) reported taking no specific steps to prepare themselves or their EYA for the transition to college, believing that the transition to independence was more of a gradual, subtle process that began at the time of diagnosis. Parents of EYAs who completed the transition to college (chapter 4) were surprised to find that they were still serving as a back-up responder for T1DM concerns.

Mothers before the transition (chapter 3) and parents after the transition (chapter 4) reported varying degrees of involvement with their EYA's daily T1DM management. While all parents reported working to promote independence, parents both before (chapter 3) and after the college transition (chapter 4) continued to assist their EYA with daily T1DM tasks such as site changes and carbohydrate counting. Parents of high school seniors (chapter 3) who perceived that their EYA was not capable of managing their T1DM, frequently reported "spying" or "snooping" through their EYA's belongings to check blood glucose levels or to ensure that they were maintaining T1DM related snacks and supplies, inadvertently reinforcing the EYA's dependence on parents. Parents after the transition (chapter 4) indicated that they would occasionally "sneak peeks" at their EYA's CGM to check blood glucose levels. This type of overparenting was seen as a facilitator to the transition.

The state of the science surrounding the barriers and facilitators experienced by parents during their EYA's transition to college with T1DM was explored in the

integrative review (chapter 2). Parental barriers in the promotion of autonomy included distress related to disagreements about responsibility for T1DM management and parental perception of the EYA's self-efficacy to manage their T1DM at college (chapter 2). While this is consistent with the findings from study one (chapter 3) and study two (chapter 4), it is important to note that no studies focused specifically on the needs of parents as they move their EYA towards independence.

The literature suggests that overparenting is associated with increased information seeking by parents, behavioral and psychological control of children by parents, and reinforced dependence on parents that may restrict autonomy and negatively affect self-efficacy in emerging adults as well as raise the risk of anxiety for parents (Luebbe et al., 2016; Padilla-Walker & Nelson, 2012; Schiffrin et al., 2014). This type of overparenting has been shown to be a risk for poor glycemic control, particularly if the EYA does not perceive the parent to be supportive, potentially leading to difficulty with letting go, hindering appropriate transitions for themselves and their EYA (Sullivan-Bolyai et al., 2014).

Current literature indicates that the transition to independent management of T1DM must be accomplished prior to the transition to college via a series of planned interventions with the support of parents as well as the diabetes care team (Agarwal et al., 2016; Lotstein et al., 2013; Majumder, Cogen & Monaghan, 2017), but the nature of this support remains largely undefined. This dissertation work revealed that EYAs are not as independent in T1DM management as parents anticipate and the transition to T1DM self-care takes much longer and is likely to be less linear in nature. This is a significant finding suggesting that diabetes care providers view the preparation for the

college transition as a lengthy process and consider the parental needs well beyond the transition from adolescence into early adulthood.

### **Parental Communication in the Transition to College with T1DM**

Before the college transition (chapter 3), parents indicated that they planned to require their EYA to wear a continuous glucose monitor (CGM) while at college or were planning to insist their EYA communicate via text with blood glucose readings daily, both in the morning and evening. However, parents both before (chapter 3) and after the college transition (chapter 4) indicated that communication with EYAs began to diminish significantly during this time, adding to parental distress. While mothers prior to the college transition (chapter 3) occasionally reported difficulty communicating about their EYA's T1DM, parents after the college transition (chapter 4) indicated that this was a constant concern, particularly when EYAs removed and/or restricted access to CGMs.

Parents of college students (chapter 4) frequently reported watching their EYA's blood glucose levels decrease rapidly on their CGM and feeling helpless. These decreases in blood glucose levels typically occurred during the overnight hours and were often related to excessive alcohol consumption. This distress led parents to contact resident assistants or campus security to arouse their EYA to take action to correct their blood glucose. After the college transition (chapter 4), some parents determined that this level of T1DM management was not healthy for them or their relationship with their EYA and ultimately loosened their management parameters and expectations. Increased parental distress related to decreased communication lack of information from the EYA about T1DM, served as a barrier to transition. Parents of EYAs who had completed the transition to college (chapter 4) indicated that this

resulted in hypervigilance which manifested in repeated attempts to discuss blood glucose management, resulting in increased conflict in the parent/EYA dyad, which led EYA's to restrict access to personal T1DM-related information, such as blood glucose levels.

Study one (chapter 3) and study two (chapter 4) both revealed that parents struggle with changing communication dynamics in the transition to college; however, this was not noted in the literature. The review of the literature supported the findings in study two (chapter 4) that indicated that parents of EYAs without a CGM felt particularly isolated; however, difficulty communicating about T1DM was not noted in the studies reviews. Parents both before (chapter 3) and after (chapter 4) the college transition indicated that communication issues were a significant barrier to transition. This body of work adds to the current literature by suggesting that parents struggle with decreased levels of communication with their EYA, leading to increased levels of parental distress.

### **Parental Need for Support in the Transition to College with T1DM**

Prior to the transition to college (chapter 3) mothers expected to receive support from their diabetes care providers. Unfortunately, this was not the case. Parents of EYAs who had completed the transition to college (chapter 4) reported limited support from diabetes care providers and any support available was directed towards the EYA with a focus on accommodations in the college setting. This lack of support led parents to search for information and resources regarding preparation for the college transition, such as packing lists and helpful tips, from other sources such as the College Diabetes Network (CDN) parent Facebook group and other T1DM

Facebook groups. Parents before (chapter 3) and after the college transition (chapter 4) also sought support via the CDN and JDRF websites.

Parents of EYAs who had completed the transition to college (chapter 4) indicated that their needs, both emotional and practical, including packing lists, were typically not addressed by the EYA's diabetes care provider. Diabetes care providers informed parents of college students (chapter 4) that T1DM was their "child's disease" and he/she needed to manage it; however, no guidance or support was provided for parents which left them feeling isolated and without support during their EYA's transition to college. This general lack of guidance from diabetes care providers and concerns about multiple distractions at college including academics, social interactions, and risky behaviors, served as a barrier to the transition.

Parents before the college transition (chapter 3) maintained supportive relationships with school nurses as well as school administrators and hoped to create similar relationships in the college setting. Parents after the transition to college (chapter 4) found that this type of support was not available and expressed the desire to have a connection to a responsible, supportive adult on campus with knowledge of T1DM. This isolation led parents after the college transition (chapter 4) to attempt to make connections with services available on campus, such as disability services and student health services; however, their efforts were largely unsuccessful.

Parents of high school seniors (chapter 3) reported contacting their EYA's college or university to discuss potential accommodations with the office of disability services; however, these contacts were more about information gathering than actual arrangements. Federal law requires that students must request accommodations in the academic setting themselves. This lack of connection to a campus professional that

could serve as a link between the EYA and the parent added to distress experienced by parents of high school seniors. This concern was echoed by parents of students who had completed the transition to college (chapter 4); however, they unexpectedly found support through their EYA's roommate and/or social network.

The literature review (chapter 2) revealed that while parental support for EYAs transitioning with T1DM is an integral part of the transition process, there were few studies focused on parents' needs as they attempt to support their EYA during their move towards self-management. Literature reviewed identified stressors related to the promotion and development of autonomy; however, no studies focused specifically on support for parents as they move their EYA towards independence in T1DM management. Parents who are not able to manage their own transition may have difficulty supporting their EYA during their transition to college, particularly those who continue to need high levels of support in T1DM management (Akre & Suris, 2014; Hessler et al., 2016; Livesey & Rostain, 2017; McGoldrick et al., 2015). This was a significant finding as parents who are able to manage their own transition to parent of a college-bound EYA with T1DM may result in decreased levels of stress during this time, which may support a positive transition for both parent and EYA as they move to the next stage of life (Akre & Suris, 2014; McGoldrick et al., 2015).

### **Limitations**

While this research highlights the concerns that parents have as their EYA with T1DM transitions to college, several limitations must be acknowledged. First, these studies did not address varying demographic and psychosocial factors that may impact those with T1DM during the transition to college, including single parent homes, families from different cultures or different parts of the country; therefore, findings

may not be generalizable to the entire population. Due to the fact that recruitment only included parents of college bound emerging adults with T1DM, these findings may not be generalizable to parents of emerging adults with type 2 diabetes. These findings did not account for EYAs who attend college but live at home, those who are directly entering the workforce, or those who are not under the care of established endocrine practices.

Second, while the two data-based studies compare and contrast the experience of parents of EYA's with T1DM before and after the transition to college, these samples are not truly pre and post samples due to the fact that only three mothers from the first study (chapter 3) participated in the second study. Third, while the use of ZOOM video conferencing strengthens the findings in the second study (chapter 4), interviews were not conducted face to face in either of the data-based studies. Fourth, this research does not take into account the health status of parents, family structure, income, race of parent or child, or employment status. Additionally, knowledge of available resources for students with T1DM at the college level was not considered.

### **Implications for Future Practice**

This research seeks to inform the parental perspective of their EYA's transition to college with T1DM. This research indicates that clinicians working with parents of college-bound youth with T1DM may want to consider the parent perspective and their potential support needs during the transition and not just focus on the EYA. Parents must progress through their personal transition during this time, as delaying the transition process for parents may lead to unresolved psychosocial and physical health crises, including difficulty with relationships and future transitions.

Parents expressed high levels of concern regarding their EYA's ability to manage their T1DM while at college. This concern led to unwillingness to relinquish control of all aspects of diabetes management, with several parents still serving as back-up care during the overnight hours or in emergencies. Diabetes care providers working with families as they approach the transition to college should work to gain a better understanding about the ability of the EYA to manage their T1DM while away at college. In order for parents to relinquish control and support autonomy, parents need to feel that their EYA is capable of managing their T1DM independently. Clinicians could consider a screening questionnaire to evaluate the EYA's ability to self-manage as well as a tool to gauge parental readiness to relinquish control of T1DM management. As parents continue to serve as partners in T1DM management through the college transition, diabetes care providers must provide education regarding alcohol consumption and its impact on blood glucose to both parents and EYAs.

Parents indicated a general lack of support from diabetes care providers as well as colleges/universities before, during, and after the college transition. This was particularly true for parents of EYAs who had already transitioned to adult providers. This research indicates that providers working with EYAs during the college years may want to consider the needs of the parent during college transition. Additionally, this research has shown that continued parental involvement in T1DM management leads to better glycemic control for EYAs and decreased stress for parents. Diabetes care providers could consider offering parents information specific to the transition to college including appropriate levels of management, steps parents can take to support their EYA during their college years, and education regarding the types of

accommodations available at college. Colleges and universities could consider providing additional information for parents during the transition process such as available T1DM resources on campus, steps to take in case of a diabetes-related emergency and local health care services.

### **Implications for Future Research**

This research explored the parent experience as they transitioned their EYA with T1DM to college. Parents both before and after the college transition identified several concerns as they transitioned their EYA towards independence in preparation for college. Additional studies are needed to develop interventions to support parents during this time.

These studies explored the parent experience as they prepared their EYA to transition to college with T1DM. Parents both before and after the college transition expressed concerns regarding their EYA's ability to manage their T1DM in the college setting. Previous research has determined that parents continue to serve as partners in T1DM management (Carcone et al., 2012; Hanna, Dashiff et al., 2013; Lokes, Gingras, Philippe, Koestner, & Fang, 2010; Moreira & Canavarro, 2016; Schultz & Smaldone, 2017), but the expectations and limitations of this partnership are not well defined. Evolving roles in the parent/EYA dyad, including balancing holding on and letting go and changing communication dynamics complicate this shift from serving as a partner in T1DM management to serving in a consulting role as the EYA transitions to college.

While this research indicated that the relationship between parent and EYA is a facilitator in the transfer of responsibility for management of T1DM, future research is needed to compare and contrast the experience of each member of the dyad during this

time. A qualitative study focused on the relationship between parents and EYAs and its impact on T1DM management during the transition to college will foster a deeper understanding of this dyadic perspective and lead to the development of informed family-centered interventions designed to promote autonomy for EYAs and increase parental willingness to let go. Additional research could be conducted to validate a tool to assist providers in identifying parent readiness to let go.

This research also identified lack of provider support as a significant barrier experienced by parents during their EYA's transition to college with T1DM. While this dissertation identified areas where support is lacking, the nature of the desired amount and type of support is undefined. Parents indicated that they received limited support from diabetes care providers. Support received was generally directed at the EYA and focused primarily on accommodations in the college setting. Unfortunately, this left parents feeling isolated during the transition process, leading parents to seek out other sources of support including non-profit diabetes organizations and online support groups. Parents reported seeking and receiving the majority of their support from online sources such as Facebook. A national quantitative study identifying the types of support received from online sources would be beneficial to assist diabetes care providers as they endeavor to inform parents during the college transition process.

This research did not account for EYA's residing in single parent homes, families from different cultures or different parts of the country, EYAs who attend college but live at home, those who are directly entering the workforce, or those who are not under the care of established endocrine practices. Additional research focused on these populations would be beneficial to determine if the support needs are

different or if more targeted interventions are necessary to facilitate the transition to adulthood.

In addition, this research revealed a general disconnect between parents and the college environment. Parents indicated that they felt disconnected and alone with no on-campus contacts or support as their EYA completed the transition process. Further research should be conducted to determine the types of support offered by colleges and universities to assist parents as they transition their EYA with T1DM to college.

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## Appendix B

### PERMISSION TO USE-STUDY ONE

Use of manuscript in dissertation

Michelle Ness <mness@udel.edu>

Fri, Jul 12,  
12:34 PM

Good afternoon-

I am seeking permission to use the manuscript version of my article "Maternal Experiences of Transitioning Their Emerging Adult to College" The Diabetes Educator, Vol.44, Issue 2. (doi.org/10.1177/0145721718759980) in my dissertation. I think I can use the full text, but I need it in manuscript format and need evidence of permission. I apologize in advance if this is a silly question, but how do I go about obtaining that? May I just use the word version of my accepted article? Thank you in advance for your assistance.

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Mon, Jul 15,  
1:43 PM

to me

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## Appendix C

### INSTITUTIONAL REVIEW BOARD APPROVAL-STUDY ONE



RESEARCH OFFICE

210 HULLIHEN HALL  
UNIVERSITY OF DELAWARE  
NEWARK, DELAWARE 19716-1551  
Ph: 302/831-2136  
Fax: 302/831-2828

DATE: April 25, 2017

TO: Michelle Ness, MSN, RN  
FROM: University of Delaware IRB

STUDY TITLE: [1056747-1] Exploring Parent Experiences as their Children with Type 1 Diabetes Transition from High School to College

SUBMISSION TYPE: New Project

ACTION: APPROVED  
APPROVAL DATE: April 25, 2017  
EXPIRATION DATE: April 24, 2018  
REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # (6,7)

Thank you for your submission of New Project materials for this research study. The University of Delaware IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the study and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the appropriate adverse event forms for this procedure. All sponsor reporting requirements should also be followed.

Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.

Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office on an annual basis. Please use the appropriate renewal forms for this procedure.

If you have any questions, please contact Nicole Farnese-McFarlane at (302) 831-1119 or [nicolefm@udel.edu](mailto:nicolefm@udel.edu). Please include your study title and reference number in all correspondence with this office.

## Appendix D

### INSTITUTIONAL REVIEW BOARD APPROVAL-STUDY TWO



Institutional Review Board  
210H Hullahen Hall  
Newark, DE 19716  
Phone: 302-831-2137  
Fax: 302-831-2828

DATE: June 6, 2019

TO: Michelle Ness, MSN, RN  
FROM: University of Delaware IRB

STUDY TITLE: [1447047-1] Perceived Barriers and Facilitators in the Transition to College with Type 1 Diabetes Mellitus

SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS

EFFECTIVE DATE: June 6, 2019

REVIEW CATEGORY: Exemption category # (2)

Thank you for your New Project submission to the University of Delaware Institutional Review Board (UD IRB). According to the pertinent regulations, the UD IRB has determined this project is EXEMPT from most federal policy requirements for the protection of human subjects. The privacy of subjects and the confidentiality of participants must be safeguarded as prescribed in the reviewed protocol form.

This exempt determination is valid for the research study as described by the documents in this submission. Proposed revisions to previously approved procedures and documents that may affect this exempt determination must be reviewed and approved by this office prior to initiation. The UD amendment form must be used to request the review of changes that may substantially change the study design or data collected.

Unanticipated problems and serious adverse events involving risk to participants must be reported to this office in a timely fashion according with the UD requirements for reportable events.

A copy of this correspondence will be kept on file by our office. If you have any questions, please contact the UD IRB Office at (302) 831-2137 or via email at [hsrb-research@udel.edu](mailto:hsrb-research@udel.edu). Please include the study title and reference number in all correspondence with this office.

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