



Barriers and Facilitators Influencing Parental Transition of College-Bound Youth with Type 1 Diabetes Mellitus: An Integrative Review

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Abstract

Purpose of Review 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.

Recent Findings Seven studies, 5 qualitative and 2 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.

Summary 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 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.

Keywords Type 1 diabetes · Parents · Transition · College

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 15–24 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 that 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

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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 U.S.; 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, remain 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 healthcare; 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 and facilitators 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 Knafel'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 HCPs, while only one study [21] focused exclusively on the

Table 1 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) [29]	<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 health care professionals' (HCPs) of the transition process for young adults with type 1 diabetes 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) [30••]	<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 type 1 diabetes (T1D).	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.
Ness et al. (2018) (United States) [21]	<i>N</i> = 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) [31••]	<i>N</i> = 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 T1D management), and resources used to manage T1D.	Qualitative. (Focus groups).	Teen and parent perspectives are critical in designing future well-received adolescent-family transition clinics.
Ersig et al. (2016). (United States) [32••]	<i>N</i> = 40 teens and parents: mean age of teens not indicated.	The purpose of this study was to identify stressors of teens with type 1 diabetes (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) [33]	<i>N</i> = 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.

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

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-related 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 three 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, 32••]. 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 [33].

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, 32••]. 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 [29], 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 [30••]. In a study of 332 parents focused on T1DM-related stress, 88.9% of parents indicated that they experienced a least "a little" distress and 56.9% indicated "moderate" or higher levels of distress related to concerns about youth T1DM self-management [33]. 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 [29].

Limited access to health care 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 [31••]. 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 [31••]. This angered both parents and youth and led to a fear of being honest with HCPs [31••]. Parents indicated they would like more information about how to plan for college and manage T1DM in the college setting [31]. 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 [29].

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 [31••, 32••]. 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 U.S. 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) [31]. 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 [33]. 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" [31••] p. 187].

Distress

Both qualitative and quantitative studies indicate that lack of support for parents leads to higher levels of distress related to T1DM management [21, 29, 33]. A quantitative study of 332 parents in the U.S. indicated that sources of parental T1DM distress included personal distress, youth management issues, parent/youth relationship dynamics, and concerns about the

healthcare team [33]. 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 U.K. echoed these concerns. Parents of youth age 12–18 with higher hemoglobin A1c had higher levels of parental distress ($r = .26, p < .001$) [30••]. 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 [30••]. Conversely, lower levels of parental distress were associated with higher youth self-efficacy ($r = -.28, p < .001$) [30••], parental perceptions of youth self-efficacy ($r = -.43, p < .001$) [30••], and increased agreement of responsibility for T1DM self-management activities ($r = -.21, p < .01$) [30••].

Parents indicated that, despite taking steps to ensure that their youth could manage their T1DM management on their own, they continue to worry [21, 32••, 33]. 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, 29]. 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)” [32••]. 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 p. 182].

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, 32••], and given that hemoglobin A1c increases and blood glucose monitoring decreases as youth assume T1DM management responsibilities, these concerns are often well-founded [33].

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, 32••]. Research reviewed clearly demonstrated that parental support for youth transitioning with T1DM is an integral part of the transition process [28, 29, 31••, 32••, 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, 32••]; thus many parents restrict the college choices or delay their departure from home to ensure proximity to HCPs [32••]. 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 p. 393].

While the T1DM literature reviewed discusses stressors related to the promotion and development of autonomy [28, 29, 30••, 31••, 32••, 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, 32••]. 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 [33]. 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 [31, 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 [31, 33].

Parents and youth were found to share the same concerns of safety, attaining normality, striving for independence, and worry about the future, although 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, 29, 33]. 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 [29]. 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 with their youth’s T1DM management as they are 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 healthcare. Only one study focused exclusively on the parent perspective of transition 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 parent and youth.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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