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An Exploratory Study: Transition to Adulthood for College Students with Type 1 Diabetes and Their Parents☆

Anne L. Ersig, PhD, RN

The University of Wisconsin-Madison, School of Nursing, Madison, WI, United States of America.



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ABSTRACT

Purpose: The transition to college and adulthood can be challenging for young adults with chronic health conditions and their parents. Few studies have simultaneously explored the experiences of college students and their parents during the transition to college. The purpose of this study was to explore the transition to adulthood for college students with type 1 diabetes (T1D) and their parents.

Design and methods: A descriptive exploratory study was conducted with college students with T1D and their parents. Data were collected online using quantitative surveys and open-ended questions. Descriptive statistics were generated for quantitative measures. Analysis of responses to open-ended questions used qualitative description.

Results: College students (18–24 years) and parents described challenges with life-stage stress, diabetes management worries, and concern about T1D-related long-term complications. Respondents also described the critical role of the college peer network for support and help in case of crisis situations. Students reported stress related to uncertainty in diabetes management, while parents described constant worry about their child's diabetes.

Conclusions: Findings support the importance of assessing anticipated and current stressors of college students with T1D and other chronic health conditions and their parents during and after transition to college.

Practice implications: Nurses can support students and parents by providing anticipatory guidance about the transition to college. Assistance identifying established sources of support on college campuses, as well as planning for potential crisis situations, may help reduce stress experienced by students and parents.

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The transition to college and adulthood is stressful for many emerging adults; for those with chronic health conditions such as type 1 diabetes (T1D), it can be even more challenging (Monaghan, Helgeson, & Wiebe, 2015; Ness, Saylor, & Selekman, 2018). Emerging adults are defined as individuals who are 18–25 years old, an age range that includes many college students (Arnett, 2007). Although college students with T1D and other chronic health conditions generally know how to manage their conditions, they struggle to incorporate appropriate management into their changing lives (Balfe, 2009; Fredette, Mawn, Hood, & Fain, 2016; Monaghan et al., 2015). This raises risks of potential crises such as life-threatening hypoglycemia (Awoniyi, Rehman, & Dagogo-Jack, 2013). Nearly 6% of college undergraduates report having a chronic illness (American College Health Association, 2018), making the combined impact of potential condition-related difficulties substantial. Despite these risks, knowledge of the experiences of emerging

adults with T1D and other chronic health conditions and their parents during the transition to college in the US remains limited, with studies evaluating clinical outcomes in lieu of students' and parents' perspectives, or focusing on health care transition (Garvey et al., 2017; Ness et al., 2018).

Transition from a structured home environment to the more unpredictable college setting may be particularly challenging for emerging adults whose conditions have complex management regimens. Establishing new routines and support networks requires adjusting and adapting throughout college (Balfe, 2009; Hill, Gingras, & Gucciardi, 2013; Saylor, Hanna, & Calamaro, 2019). Challenges of college students with T1D include meeting academic requirements, incorporating diabetes management into inconsistent schedules, navigating large college campuses, obtaining healthy food, and establishing new social networks (Fredette et al., 2016; Saylor et al., 2019). Type 1 diabetes can affect students' abilities to concentrate, participate in classes and meet academic requirements (Fredette et al., 2016). A less consistent schedule, large campuses, limited time between classes, and participating in other activities can make testing blood sugars and obtaining healthy food, particularly from dining halls, difficult (Balfe, 2009; Fredette et al., 2016; Habenicht, Gallagher, O'Keeffe, & Creaven, 2018; Saylor et al., 2019).

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E-mail address: anne.ersig@wisc.edu.

The transition to adulthood is also marked by substantial shifts in relationships and social networks (Habenicht et al., 2018; Sparud-Lundin, Öhrn, & Danielson, 2010). Emerging adults with T1D and their parents experience significant stress due to changing relationships (Betz, Nehring, & Lobo, 2015; Fredette et al., 2016; Hessler, Fisher, Polonsky, & Johnson, 2016; Wiebe, Berg, Mello, & Kelly, 2018). Many parents extensively involved in condition management since diagnosis limit their involvement with the impending transition to adulthood, but find this difficult (Betz et al., 2015; Fredette et al., 2016; Ness et al., 2018; Sparud-Lundin et al., 2010; Wiebe et al., 2018). Parents struggle to balance the young adult's need for independence with continuing to provide insights, advice, and support, which is associated with better diabetes management outcomes (Monaghan et al., 2015; Ness et al., 2018; Sparud-Lundin et al., 2010). Anticipating the transition to adulthood generates substantial stress in parents of teens with T1D (Ersig, Tsalikian, Coffey, & Williams, 2016; Ness et al., 2018); however, few studies have examined stress of parents whose children are already in college.

College students with T1D also initiate relationships with a new set of peers (Hill et al., 2013; Zarrett & Eccles, 2006), who are less knowledgeable about T1D than the high school social network, and must be taught about T1D, potential complications, and appropriate responses (Fredette et al., 2016). Although greater peer support is associated with better T1D management and outcomes (Hessler et al., 2016; Wiebe et al., 2018), emerging adults may limit diagnosis disclosure in new relationships in an effort to seem “normal”, leading to less support (Habenicht et al., 2018; Helgeson et al., 2015; Hill et al., 2013). This can pose challenges in emergencies (Hill et al., 2013): alcohol use increases risks for severe hypoglycemia, which can mimic intoxication (Monaghan et al., 2015), and can lead to inappropriate management, such as failure to adjust insulin doses to reflect alcohol intake.

High stress during the transition to adulthood is associated with worse T1D management and control (Baucom et al., 2015; Butler et al., 2017; Hanna, Weaver, Slaven, Fortenberry, & DiMeglio, 2014). This may be due to high cumulative stress from a combination of typical transition stressors (e.g., career decisions) and diabetes-specific stress (Butler et al., 2017; Hill et al., 2013; Monaghan et al., 2015). Diabetes-specific stressors also change during the transition to adulthood, and include challenges obtaining support from social networks and providers, worries about severe hypoglycemia and concern about eating behaviors (Ersig et al., 2016; Fisher et al., 2015; Hilliard et al., 2016). Although independent self-management of T1D is a key transition milestone (Monaghan et al., 2015; Saylor et al., 2019), perceived diabetes management failures are stressful, increase risk of depressive symptoms and anxiety (Fisher et al., 2015; Mullins et al., 2017), and are associated with worse adherence and outcomes, particularly among emerging adults who move out of their parents' homes (Baucom et al., 2015; Baucom, Turner, Tracy, Berg, & Wiebe, 2018; Hanna et al., 2014; Monaghan et al., 2015). Studies that have evaluated everyday and diabetes-specific stressors of college students with T1D and their parents focus on clinical outcomes, such as glycemic control (Butler et al., 2017; Hanna et al., 2018; Hilliard et al., 2016); knowledge of parents' and students' personal stress experiences is more limited (Balfe, 2009). Identifying important stressors will support developing and implementing interventions to alleviate stress and improve mental and physical health (Epel et al., 2018).

Type 1 diabetes can serve as an exemplar for chronic health conditions requiring sustained, consistent management and with higher risks of crisis situations. Learning about the experiences of emerging adults with T1D and their parents during the transition to college and adulthood will provide important insights into the stress experienced at this key developmental stage and approaches to supporting chronic condition management in the college environment, and will help identify areas for intervention. Multiple studies have explored the transition from pediatric to adult health care services; in contrast, this study takes

a broader perspective of the transition to adulthood (Chiang et al., 2018; Garvey et al., 2017; Sheehan, While, & Coyne, 2015).

Purpose of this study

The purpose of this study was to explore the transition to adulthood for college students with T1D and their parents. Emerging adults and their parents answered open-ended questions and completed measures of quality of life and anxiety.

Methods

Procedure

The parent study in which these data were obtained was a mixed methods exploratory study of college students with severe food allergy or T1D and their parents. The parent study was approved by the University of Iowa Institutional Review Board. Data on emerging adults with food allergy and their parents have been reported (Ersig & Williams, 2018). This analysis focuses on 18–24 year old college students with self-reported T1D and their biological parents, stepparents, or parent figures. Parents' participation was not required; results are reported from emerging adults with and without participating parents. Students were recruited through mass emails at 3 colleges and through the Facebook page for the College Diabetes Network (CDN; <https://www.facebook.com/collegediabetesnetwork/>). Students interested in the study completed an enrollment survey to determine eligibility; those who had one of the chronic conditions of interest were sent a generic survey link. The enrollment survey asked students to determine if their parent(s) were interested in participating. Those whose parents expressed willingness to participate provided parents' emails. Parents were emailed study information and a link to the parent survey. As this was an exploratory descriptive study, we did not conduct a formal power analysis (Sim & Lewis, 2012).

Instruments

Data were gathered online using a secure online platform (Qualtrics; <https://www.qualtrics.com/>) for surveys and open-ended questions. Surveys assessed state and trait anxiety for students and parents using the 40-item State-Trait Anxiety Inventory (STAI). The STAI has established reliability and validity for college students and working adults. Mean reliability scores were 0.91 (state) and 0.89 (trait), and mean test-retest reliability scores were 0.7 (state) and 0.88 (trait) in a generalizability study (Barnes, Harp, & Jung, 2002). Students completed the PedsQL Diabetes Module 3.2 as a reliable (coefficients 0.88–0.9) and valid measure of diabetes-specific quality of life used frequently with young adult samples. Validity was established through comparison to other measures of quality of life (Varni et al., 2018). Students also answered five questions from the Pediatric Diabetes Routines Questionnaire (PDRQ) (Pierce & Jordan, 2012) to assess T1D management routines. Selected questions assessed emerging adults' routines for adhering to T1D regimens, blood sugar testing, and carrying emergency supplies, as well as treating high and low blood sugars; face validity of selected questions was established through clinical expert review. Three open-ended questions based on an earlier study of teens with T1D and their parents (Ersig et al., 2016) explored everyday and chronic illness-related stressors, and plans for responding to a T1D-related crisis: “What in your everyday life stresses you out?”; “What about your (child's) diabetes stresses you out?”; and “What is your (child's) plan for responding to a crisis situation related to T1D while at college?” (Ersig et al., 2016).

Analyses

Deidentified responses to survey questions were imported into software for analysis. Descriptive statistics were generated for quantitative

measures using SPSS 25. Scale scores were calculated for the state and trait scales of the STAI, PedsQL 3.2 Diabetes Module, and five selected items from the PDRQ. Scores were compared to available normative data or scores from individuals with chronic health conditions or their parents, as appropriate. Qualitative descriptive analysis was used to examine responses to open-ended questions using Atlas.ti software (Atlas.ti, 2018; Sandelowski, 2000, 2010). The principal investigator for the study read text responses for each question were read and preliminary content-based codes applied, then re-examined to eliminate redundancy and identify overarching themes. A PhD student trained in qualitative analysis reviewed coding to ensure completeness and accuracy. Codes and themes were revised until author and student reviewer reached consensus.

Results

Twenty-five 18–24 year old college students with self-reported T1D and 14 parents completed online surveys that included quantitative measures and open-ended questions. Twelve parents had children participating in the study, and were from 8 families. One unpaired parent was recruited through a college student who chose not to participate, while the other was recruited through the CDN Facebook page. Detailed demographic information for emerging adults and parents is provided in Table 1.

Mean STAI scores for state and trait anxiety for students and parents are reported in Table 2. Means for emerging adults (state 40.4 ± 9 , range 26–59; trait 43.4 ± 8.9 , range 25–60) and parents (state 39.9 ± 7.8 , range 28–55; trait 38.4 ± 7.1 , range 23–50) were higher than published norms (Spielberger & Gorsuch, 1983) for college students and working adults, respectively, but similar to those from students with food allergy in the parent study. Students' mean scores on the PedsQL Diabetes Module 3.2 were lower than recently reported means

Table 1
Respondent demographics.

Emerging adults		
Variable	N	%
Male ($n = 23$)	4	17.4%
Race ($n = 25$)		
White	21	84%
Other	1	4%
Prefer not to answer	3	12%
Year in college ($n = 11$)		
Underclassmen	6	54.5%
Upperclassmen	5	45.4%
Crisis situation at college ($n = 25$)	10	40%
Have a plan for crisis at college ($n = 25$)	23	92%
Have a health care provider for T1D ($n = 25$)	24	96%
Health care provider located at college ($n = 23$)	9	39.1%
Parents of emerging adults with T1D – demographics		
Variable	N	%
Male ($n = 11$)	4	36.4%
Race ($n = 14$)		
White	11	78.6%
Other	3	21.4%
Marital Status ($n = 11$)		
Married	9	81.8%
Divorced	1	9%
Living with a partner	1	9%
Education ($n = 11$)		
Less than bachelor's degree	5	45.5%
Bachelor's degree	3	27.3%
Graduate degree	3	27.3%
Employment status ($n = 11$)		
Full time	9	81.8%
Part time	2	18.2%
Child has a plan for crisis at college ($n = 13$)	13	100%

N for response to each question varies; row percentages based on number of participants who provided a response to each question.

Table 2
Anxiety, quality of life, and diabetes routines.

	Emerging adults	Parents
	Mean \pm SD (range)	Mean \pm SD (range)
STAI-State	40.4 ± 9 (26–59)	39.9 ± 7.8 (28–55)
STAI-Trait	43.4 ± 8.9 (25–60)	38.4 ± 7.1 (23–50)
PedsQL diabetes module ^a		
Symptom subscale	55.65 ± 11.72 (25–73.33)	
Management subscale	69.68 ± 14.86 (41.67–97.22)	
Diabetes routines (PDRQ) ^b	19.22 ± 3.2 (13–24)	

^a Lower scores indicate lower quality of life.

^b Responses to five selected questions; lower scores indicate less consistent routines. Scale maximum 25.

of adolescents and emerging adults with T1D (Varni et al., 2018), reflecting poorer quality of life. Students' mean scores for the 5 selected questions from the PDRQ were lower than those obtained from students with severe food allergies in the parent study (unpublished data), indicating less consistent routines.

Four primary themes were identified in responses to open-ended questions: (1) life stage stress; (2) diabetes management worries; (3) long-term implications and complications; and (4) the importance of the college-based social network. Two subthemes were identified for diabetes worries in everyday life. Subtheme 1 was specific to students and reflected uncertainty in T1D management, while subtheme 2 identified diabetes as a constant worry in parents.

Life stage stress

For emerging adults, life stage stress focused on typical college life, and included concerns about classes and grades, social relationships, and life after college. Parents, in contrast, described stressors related to being members of a “sandwich generation” (Lansford, 2018), citing worries about their parents, their own lives, and their children's lives.

College students with T1D experienced stress related to college life in general. These included the pressures of “constant schoolwork” (Student 1), and “having enough time to get everything done that I need to get done” (Student 2). Friends and social lives were also challenging; one student expressed difficulty “balancing school and social life” (Student 3), while another stated that “...my roommates aren't very happy with me because I am gone all the time studying, it is very frustrating and stressful” (Student 4). Life after college was a prominent concern; one student described “thoughts about the future, future employment, and achieving my hopes and dreams” (Student 5).

Parents' concerns, in contrast, focused on balancing work, home life, and worries about their own parents and children, both with and without diabetes. One mother said she was stressed out by “getting everything done at home while working, monitoring children's lives. Parents aging” (Parent 1), while another described challenges “balancing full-time work with 3 kids, both parents with extensive international business travel and two kids with T1D” (Parent 2).

Diabetes management worries

For students, daily diabetes management was an ongoing concern. They focused on challenges with daily management tasks, attaining and maintaining control of blood sugars to allow full participation in college life, and the impact of these actions and their outcomes on their everyday lives. Anticipated or actual fluctuations in blood sugars were major issues; these were particularly stressful when they occurred despite appropriate T1D management. As one student described, “keeping my blood sugar in range is pretty stressful for me. I have become so busy that I completely forget to check my blood sugar for hours and my schedule changes every day so I have a hard time keeping my blood sugars in control” (Student 6). Another stated, “when I have a stressful day with a lot of school work, exams, or extracurriculars and I

test my blood sugar and find that it is either high or low, it adds immense stress onto my day” (Student 7). Even sleep was viewed as potentially risky, with another student stressed by the possibility of “going low while asleep and having no one around to help” (Student 8). Lack of information on carbohydrate counts in dining halls made blood sugar management even more difficult, with multiple students reporting guessing on carb counts.

Parents’ worries about diabetes in everyday life focused on their child’s management of T1D in the college environment, and whether the outlined plan was being followed. One father described common concerns, wondering whether his child was “...taking the right insulin when needed and keeping her blood sugars where they should be” (Parent 3). Parents also mentioned concerns specific to college life. As one parent (Parent 8) said, “I worry about her blood sugars and if she is eating the right things and taking her shots when needed. I worry about her drinking like most kids do at this age. I try to discourage her from the alcohol which I think she does try to, but there is times I know she wants to be part of the crowd.” Alcohol and maintenance of blood sugars were a concern for several parents, who worried about “having someone mistake a hypoglycemic episode for drunkenness or drug use and not getting her the help she needs” (Parent 4).

Subtheme 1: uncertainty in college student T1D management

Emerging adults were frustrated and concerned by the uncertainty inherent in blood sugar management and control. As one described: “The fact that I can’t get everything right despite my hard work – sometimes extraneous, uncontrollable conditions will impede me and I can’t do anything about it” (Student 1). “...unexplained highs or lows” (Student 9) were stressful in the present, and led to concerns about current issues raising risks of future complications: “Having 2–3 day periods of very high blood sugars is also stressful- during these times, it just won’t go down no matter the amount of insulin or exercise applied. Feeling sick and knowing that my body is being damaged is not fun times” (Student 10).

Subtheme 2: diabetes as a constant worry/source of concern for parents

Parents described diabetes as an all day, everyday concern. Even though emerging adults were away at college, parents worried about their health, well-being, and diabetes management on a daily basis. As one parent succinctly stated, “Obviously her daily health is a constant worry” (Parent 5). Another mother extensively detailed her daily diabetes-related stressors: “I have two children who are diabetic... I worry about my kids going low and dying in the night. I worry about the long term consequences or running a little high, so they don’t go low. I worry about someone slipping them something at a party or them getting drunk and being unable to care for themselves. I worry about them running out of supplies and about their devices working properly. I worry about them driving, eating properly, making good decisions. You name it. I worry a lot” (Parent 6).

Long-term implications and complications

Students and parents expressed concerns about long-term implications of having T1D, including finding good jobs with insurance, establishing relationships with supportive partners, and having children. They also worried about the impact of current diabetes management on future T1D complications. One student and her mother described similar concerns. The student worried about “...having complications (longterm), being unable to find a significant other longterm who can deal with it (longterm)” (Student 11), while her mother worried “... about all the long term consequences of diabetes. I worry if the someone they fall in love with someday will be willing to deal with life with a diabetic, pregnancy... I worry about if they will always have health insurance and if health insurance will cover all their diabetes supplies,

insulin pump and glucose monitor” (Parent 6). Students echoed these financial concerns, with one worrying about “how I’m going to pay for everything that I need related to diabetes...” (Student 8). Concern about long-term complications was prominent, with one young adult stressed by “the possibility of becoming seriously ill due to diabetic complications (not healing well, loss of vision, poor circulation, etc.)” (Student 10), and another from knowing that “...even though I take care of myself and am active, eventually the disease will overcome me” (Student 4). Another mother worried about “my son’s life expectancy, how long will have him? what if he doesn’t take care of himself like he should. He has already damaged his kidneys, what if it gets worse?” (Parent 7).

Importance of the college-based social network

Emerging adults and parents were particularly worried about crisis situations, such as severe hypoglycemia, which can mimic symptoms of intoxication. In addition to everyday and T1D-related stress, participants described plans for responding to a diabetes crisis in college.

A novel theme in these responses was reliance on members of students’ social networks for crisis-related tangible support; friends, peers, and others (e.g., coaches, resident assistants) were critical in the emergency plan. Students described educating friends and roommates about what to do if they were unresponsive, or acting strangely. “If I end up having a seizure in the middle of the night my roommate is aware of how to administer the glucagon and get help and I also wear my sensor very frequently” (Student 12). Having made the transition out of the family home, one student indicated that “the plans have changed in who I rely on most in emergency situations. I live 2000 miles from home, so I’m in control and I count on my roommate to help out in an emergency. She’s a nursing student so I trust her to know what to do...” (Student 13).

However, not all students were certain that their friends could appropriately respond to an emergency. One student realized that “I keep Glucagon in my dorm room. I actually don’t think my roommates know how to use it, but I’ve told them it treats low blood sugar” (Student 1). This student’s plan also included “...hoping that should an emergency arise, emergency medical services will be able to assist me.” Some emerging adults learned from previous experiences that they may need to revisit the plan and reeducate their friends: “After a couple of lows and my one incident I have informed my friends more and we have learned from our mistakes... We have gone more in depth on certain hypothetical situations what would you do” (Student 3).

Parents also described crisis response plans that emphasized the importance of the local, college-based social network: “(Daughter) has a couple of nursing students as roommates this past year. They seem to be concerned for her welfare when it comes to helping her with her diabetes” (Parent 8). Another parent described having multiple safeguards in place: “First all of his close friends live on the same floor and have instruction on how to handle different situations. (My son) also knows the emergency room is a half a block away and goes as soon as he feels anything coming on” (Parent 7).

Discussion

This study expands on what is known about the early stages of the transition to adulthood for college students with T1D and their parents. College serves as an initial introduction to the developmental stage of emerging adulthood for the majority of US high school students, who choose to pursue higher education (Arnett, 1994). College students may or may not view themselves as truly adults. For many, college is a protected environment in which they begin the transition to adulthood while continuing to receive support and assistance from home- and school-based resources (Zarrett & Eccles, 2006). However, college can also be stressful (Zarrett & Eccles, 2006), and students with chronic

health conditions may experience more challenges with the transition to independence and adulthood than their healthy peers (Fredette et al., 2016). Interpersonal relationships, especially parent-child relationships, shift substantially (Baete Kenyon & Silverberg Koerner, 2009). These changes can be particularly difficult for emerging adults with chronic health conditions and their parents, given parents' often extensive involvement in chronic condition management throughout childhood (Monaghan et al., 2015). Despite this, few studies of US-based college students with chronic health conditions have included both emerging adults and their parents. Despite the transition out of the family home, parents of students with T1D remain involved their lives (Monaghan et al., 2015), and may have valuable insights into the transition to college.

This study explored the experiences of the transition to college for emerging adults with T1D and their parents. Themes identified included (1) life stage stress; (2) diabetes management worries; (3) long-term implications and complications; and (4) the importance of the college-based social network.

Both students and parents described substantial everyday stress due to both life stage and T1D, potentially leading to higher cumulative stress compared to emerging adults without health conditions and their parents. While students and their parents experienced stress typical of their developmental stages, they also worried about T1D. The importance of cumulative stress and adversity is increasingly recognized (Epel et al., 2018) but often focuses on toxic stress. Cumulative chronic stress can also affect psychological, behavioral, and health-related outcomes (Juster, McEwen, & Lupien, 2010; McEwen, 2017; McEwen & Getz, 2013). A transdisciplinary model of stress (Epel et al., 2018) highlights the importance of cumulative historical and current chronic and acute stress, and could be applied to explore outcomes of cumulative stress due to a childhood chronic health condition.

Life stage-related stress of parents whose young adult children have chronic health conditions may contribute substantially to cumulative stress; however, prior studies of parents of emerging adults with chronic health conditions have not identified stressors resulting from being in the "sandwich generation". Stressors of parents with children who have a chronic health condition may differ from those of parents of healthy emerging adults, and can include continued worry about their child's health condition, their own parents' well-being, and their own lives.

A novel finding, not identified in other literature, was relying on peers and friends who do not necessarily share the T1D diagnosis for help in a diabetes-related crisis. Other studies identified fellow college students who share the young adult's diagnosis as important sources of support, advice, and help (Fredette et al., 2016; Ness et al., 2018; Ravert, Russell, & O'Guin, 2017). In contrast, students and parents in this study identified roommates, friends, and others who do not necessarily share the diagnosis. One challenge with these plans may be the importance of educating non-expert social network members about T1D management and crisis response before relying on their help in an actual crisis. While adolescents with T1D report receiving help from friends, they did not expect assistance in emergencies (La Greca et al., 1995; Peters, Nawijn, and van Kesteren, 2014). In addition, friends in one of these studies had known the adolescent for several years (Peters et al., 2014) and were familiar with T1D, which may not be the case for the newly-formed college social network.

Parents and emerging adults worried about long term complications, particularly due to less-than-ideal current diabetes management, similar to findings from other studies of adolescents and emerging adults with T1D (Fredette et al., 2016; Jacobson, 1996). Parents were especially concerned about perceived shortcomings in emerging adults' T1D management increasing risks of future complications. In addition to T1D complications later in life, parents and emerging adults also worried about future social implications, including difficulty finding jobs or partners, or having children. Emerging adults with T1D experience higher stress in romantic partnerships compared to controls, as

well as challenges establishing, maintaining, and growing these relationships, potentially due to the impact of T1D and its management (Helgeson et al., 2015). Most emerging adults with T1D view it as their responsibility, not one shared with partners (Helgeson, 2017). College students with T1D and their parents may already be aware of the impact T1D and its management can have on relationships, leading to concerns about identifying a future partner.

Finally, although two separate study questions were used to assess what the investigators referred to as "everyday" and "chronic illness related" stressors, emerging adults and parents did not make this distinction. Concerns about diabetes were seen as everyday stressors, permeating the lives of college students with T1D and their parents, and highlighting their inability to escape its effects. As one young adult stated, "Everything about this chronic disease makes life harder and stressful because at this age we're supposed to be experiencing the carefree life and exploring the world. I can't really do that with type 1 diabetes in my opinion" (Student 14).

While the number of studies examining the transition to adulthood and college for emerging adults with T1D and other chronic health conditions has expanded rapidly (Fredette et al., 2016; Ness et al., 2018; Saylor et al., 2019), this study fills an important gap by concurrently exploring experiences of emerging adults with T1D and their parents. During the transition to adulthood, parents continue to play an important role in their children's lives, and may be more involved with those who have T1D or another chronic health condition. Obtaining the perspectives of emerging adults and parents provides a comprehensive picture of the transition experience, and may help identify key areas for intervention and improvement.

Implications for future research

College students with T1D and their parents experience stress from multiple sources; future studies examining cumulative stress from multiple sources would provide important information. Future studies of parents of emerging adults with T1D should explore parental life stage stress in parents of emerging adults with T1D and other chronic health conditions, whether it differs from stress experienced by parents of healthy emerging adults, and its contribution to parents' cumulative stress. Future studies should explore the perspectives of friends and peers of emerging adults with T1D; these friends are likely naïve about the condition and appropriate crisis response. Being asked to take substantial responsibility for someone else's health and well-being may affect their own experiences of the transition to college. How families become aware of the potential links between poor T1D management and long-term complications is not known, supporting future studies exploring their origin.

Implications for nursing practice

Nurses at all levels of practice can provide important anticipatory guidance to emerging adults with T1D and other chronic health conditions and their families to help prepare for the transition to adulthood. For those planning to attend college, nurses can help identify key campus resources (e.g., student health, local providers) for assistance in emergencies. Identifying these sources of support, in addition to friends and peers on campus, will help ensure available assistance when needed. Strategizing about food options and alternatives, and ways of incorporating blood sugar testing and T1D management into busy schedules, could also facilitate the transition to college. Finally, encouraging emerging adults and their parents to meet with student disability services on campus will ensure that students have access to additional campus resources to support condition management.

Limitations of this study include a small sample size, lack of a control group, and limited diversity, affecting generalizability of results. In addition, clinical outcomes, such as measures of glycemic control, were not assessed.

Conclusions

This study fills an important gap by examining the transition to college and adulthood as experienced by emerging adults with T1D and their parents. Simultaneous data collection from both groups provides a more comprehensive overview of cumulative stress due to a lifelong chronic health condition.

CRedit authorship contribution statement

Anne L. Ersig: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Validation, Writing - original draft, Writing - review & editing.

References

- American College Health Association (2018). *American College Health Association-National College Health Assessment II: Undergraduate Student Reference Group Data Report Spring 2018*. MD: Retrieved from Silver Spring.
- Arnett, J. J. (1994). Are college students adults? Their conceptions of the transition to adulthood. *Journal of Adult Development*, 1(4), 213–224.
- Arnett, J. J. (2007). Emerging adulthood - what is it and what is it good for? *Child Development Perspectives*, 1(2), 68–73. <https://doi.org/10.1111/j.1750-8606.2007.00016.x>.
- Atlas.ti (2018). Atlas.ti Qualitative Data Analysis. Retrieved from <https://atlasti.com/>.
- Awoniyi, O., Rehman, R., & Dagogo-Jack, S. (2013). Hypoglycemia in patients with type 1 diabetes: Epidemiology, pathogenesis, and prevention. *Current Diabetes Reports*, 13(5), 669–678.
- Baete Kenyon, D., & Silverberg Koerner, S. (2009). Examining emerging-adults' and parents' expectations about autonomy during the transition to college. *Journal of Adolescent Research*, 24(3), 293–320.
- Balfe, M. (2009). Healthcare routines of university students with type 1 diabetes. *Journal of Advanced Nursing*, 65(11), 2367–2375. <https://doi.org/10.1111/j.1365-2648.2009.05098.x>.
- Barnes, L. L., Harp, D., & Jung, W. S. (2002). Reliability generalization of scores on the Spielberger state-trait anxiety inventory. *Educational and Psychological Measurement*, 62(4), 603–618.
- Baucum, K. J., Queen, T. L., Wiebe, D. J., Turner, S. L., Wolfe, K. L., Godbey, E. I., ... Berg, C. A. (2015). Depressive symptoms, daily stress, and adherence in late adolescents with type 1 diabetes. *Health Psychology*, 34(5), 522–530. <https://doi.org/10.1037/hea0000219>.
- Baucum, K. J., Turner, S. L., Tracy, E. L., Berg, C. A., & Wiebe, D. J. (2018). Depressive symptoms and diabetes management from late adolescence to emerging adulthood. *Health Psychology*, 37(8), 716–724. <https://doi.org/10.1037/hea0000645>.
- Betz, C. L., Nehring, W. M., & Lobo, M. L. (2015). Transition needs of parents of adolescents and emerging adults with special health care needs and disabilities. *Journal of Family Nursing*, 21(3), 362–412. <https://doi.org/10.1177/1074840715595024>.
- Butler, A. M., Weller, B. E., Yi-Frazier, J. P., Fegan-Bohm, K., Anderson, B., Pihoker, C., & Hilliard, M. E. (2017). Diabetes-specific and general life stress and glycemic outcomes in emerging adults with type 1 diabetes: Is race/ethnicity a moderator? *Journal of Pediatric Psychology*, 42(9), 933–940. <https://doi.org/10.1093/jpepsy/jsx092>.
- Chiang, J. L., Maahs, D. M., Garvey, K. C., Hood, K. K., Laffel, L. M., Weinzimer, S. A., ... Schatz, D. (2018). Type 1 diabetes in children and adolescents: A position statement by the American Diabetes Association. *Diabetes Care*, 41(9), 2026–2044.
- Epel, E. S., Crosswell, A. D., Mayer, S. E., Prather, A. A., Slavich, G. M., Puterman, E., & Mendes, W. B. (2018). More than a feeling: A unified view of stress measurement for population science. *Frontiers in Neuroendocrinology*, 49, 146–169. <https://doi.org/10.1016/j.yfrne.2018.03.001>.
- Ersig, A. L., Tsalikian, E., Coffey, J., & Williams, J. K. (2016). Stressors in teens with type 1 diabetes and their parents: Immediate and long-term implications for transition to self-management. *Journal of Pediatric Nursing*, 31(4), 390–396.
- Ersig, A. L., & Williams, J. K. (2018). Student and Parent Perspectives on Severe Food Allergies at College. *Journal of Pediatric Health Care*, 32(5), 445–454. <https://doi.org/10.1016/j.pedhc.2018.03.006>.
- Fisher, L., Polonsky, W. H., Hessler, D. M., Masharani, U., Blumer, I., Peters, A. L., ... Bowyer, V. (2015). Understanding the sources of diabetes distress in adults with type 1 diabetes. *Journal of Diabetes and its Complications*, 29(4), 572–577. <https://doi.org/10.1016/j.jdiacomp.2015.01.012>.
- Fredette, J., Mawn, B., Hood, K., & Fain, J. (2016). Quality of life of college students living with type 1 diabetes: A qualitative view. *Western Journal of Nursing Research*, 38(12), 1595–1610. <https://doi.org/10.1177/0193945916651265>.
- Garvey, K. C., Foster, N. C., Agarwal, S., DiMeglio, L. A., Anderson, B. J., Corathers, S. D., ... Peters, A. L. (2017). Health care transition preparation and experiences in a US national sample of young adults with type 1 diabetes. *Diabetes Care*, 40(3), 317–324.
- Habenicht, A. E., Gallagher, S., O'Keefe, M. C., & Creaven, A. M. (2018). Making the leap and finding your feet: A qualitative study of disclosure and social support in university students with type 1 diabetes. *Journal of Health Psychology*. <https://doi.org/10.1177/1359105318810875>.
- Hanna, K. M., Kaiser, K. L., Brown, S. G., Campbell-Grossman, C., Fial, A., Ford, A., ... Wilhelm, S. (2018). A scoping review of transitions, stress, and adaptation among emerging adults. *ANS. Advances in Nursing Science*, 41(3), 203–215. <https://doi.org/10.1097/ANS.0000000000000214>.
- Hanna, K. M., Weaver, M. T., Slaven, J. E., Fortenberry, J. D., & DiMeglio, L. A. (2014). Diabetes-related quality of life and the demands and burdens of diabetes care among emerging adults with type 1 diabetes in the year after high school graduation. *Research in Nursing & Health*, 37(5), 399–408. <https://doi.org/10.1002/nur.21620>.
- Helgeson, V. S. (2017). Young adults with type 1 diabetes: Romantic relationships and implications for well-being. *Diabetes Spectrum: A Publication of the American Diabetes Association*, 30(2), 108–116. <https://doi.org/10.2337/ds16-0020>.
- Helgeson, V. S., Mascatelli, K., Reynolds, K. A., Becker, D., Escobar, O., & Siminerio, L. (2015). Friendship and romantic relationships among emerging adults with and without type 1 diabetes. *Journal of Pediatric Psychology*, 40(3), 359–372. <https://doi.org/10.1093/jpepsy/jsu069>.
- Hessler, D., Fisher, L., Polonsky, W., & Johnson, N. (2016). Understanding the areas and correlates of diabetes-related distress in parents of teens with type 1 diabetes. *Journal of Pediatric Psychology*, 41(7), 750–758. <https://doi.org/10.1093/jpepsy/jsw002>.
- Hill, S., Gingras, J., & Gucciardi, E. (2013). The lived experience of Canadian university students with type 1 diabetes mellitus. *Canadian Journal of Diabetes*, 37(4), 237–242. <https://doi.org/10.1016/j.jcjd.2013.04.009>.
- Hilliard, M. E., Yi-Frazier, J. P., Hessler, D., Butler, A. M., Anderson, B. J., & Jaser, S. (2016). Stress and A1c among people with diabetes across the lifespan. *Current Diabetes Reports*, 16(8), 67. <https://doi.org/10.1007/s11892-016-0761-3>.
- Jacobson, A. M. (1996). The psychological care of patients with insulin-dependent diabetes mellitus. *New England Journal of Medicine*, 334(19), 1249–1253.
- Juster, R. P., McEwen, B. S., & Lupien, S. J. (2010). Allostatic load biomarkers of chronic stress and impact on health and cognition. *Neuroscience and Biobehavioral Reviews*, 35(1), 2–16. <https://doi.org/10.1016/j.neubiorev.2009.10.002>.
- La Greca, A. M., Auslander, W. F., Greco, P., Spetter, D., Fisher, E. B., Jr., & Santiago, J. V. (1995). I get by with a little help from my family and friends: Adolescents' support for diabetes care. *Journal of Pediatric Psychology*, 20(4), 449–476.
- Lansford, J. E. (2018). A lifespan perspective on subjective well-being. In E. Diener, S. Oishi, & L. Tay (Eds.), *Handbook of well-being*. Salt Lake City, UT: DEF Publishers. www.noba-scholar.com.
- McEwen, B. S. (2017). Neurobiological and systemic effects of chronic stress. *Chronic Stress (Thousand Oaks)*, 1. <https://doi.org/10.1177/2470547017692328>.
- McEwen, B. S., & Getz, L. (2013). Lifetime experiences, the brain and personalized medicine: An integrative perspective. *Metabolism*, 62(Suppl. 1), S20–S26. <https://doi.org/10.1016/j.metabol.2012.08.020>.
- Monaghan, M., Helgeson, V., & Wiebe, D. (2015). Type 1 diabetes in young adulthood. *Current Diabetes Reviews*, 11(4), 239–250.
- Mullins, A. J., Gamwell, K. L., Sharkey, C. M., Bakula, D. M., Tackett, A. P., Suorsa, K. I., ... Mullins, L. L. (2017). Illness uncertainty and illness intrusiveness as predictors of depressive and anxious symptomatology in college students with chronic illnesses. *Journal of American College Health*, 65(5), 352–360. <https://doi.org/10.1080/07448481.2017.1312415>.
- Ness, M. M., Saylor, J., & Selekmann, J. (2018). Maternal experiences of transitioning their emerging adult with type 1 diabetes to college. *The Diabetes Educator*, 44(2), 178–187. <https://doi.org/10.1177/0145721718759980>.
- Peters, L. W., Nawijn, L., & van Kesteren, N. M. (2014). How adolescents with diabetes experience social support from friends: Two qualitative studies. *Scientifica (Cairo)*, 2014, 415849. <https://doi.org/10.1155/2014/415849>.
- Pierce, J. S., & Jordan, S. S. (2012). Development and evaluation of the pediatric diabetes routines questionnaire. *Children's Health Care*, 41(1), 56–77.
- Ravert, R. D., Russell, L. T., & O'Guin, M. B. (2017). Managing chronic conditions in college: Findings from prompted health incidents diaries. *Journal of American College Health*, 65(3), 217–222. <https://doi.org/10.1080/07448481.2016.1266640>.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340.
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health*, 33(1), 77–84.
- Saylor, J., Hanna, K. M., & Calamaro, C. J. (2019). Experiences of college students who are newly diagnosed with type 1 diabetes mellitus. *Journal of Pediatric Nursing*, 44, 74–80.
- Sheehan, A., While, A., & Coyne, I. (2015). The experiences and impact of transition from child to adult healthcare services for young people with type 1 diabetes: A systematic review. *Diabetic Medicine*, 32(4), 440–458.
- Sim, J., & Lewis, M. (2012). The size of a pilot study for a clinical trial should be calculated in relation to considerations of precision and efficiency. *Journal of Clinical Epidemiology*, 65(3), 301–308.
- Sparud-Lundin, C., Öhrn, I., & Danielson, E. (2010). Redefining relationships and identity in young adults with type 1 diabetes. *Journal of Advanced Nursing*, 66(1), 128–138.
- Spielberger, C. D., & Gorsuch, R. L. (1983). *State-trait anxiety inventory for adults: Manual, instrument, and scoring guide*. Mind Garden, Incorporated.
- Varni, J. W., Delamater, A. M., Hood, K. K., Raymond, J. K., Chang, N. T., Driscoll, K. A., ... Faith, M. A. (2018). PedsQL 3.2 diabetes module for children, adolescents, and young adults: Reliability and validity in type 1 diabetes. *Diabetes Care*, 41(10), 2064–2071.
- Wiebe, D. J., Berg, C. A., Mello, D., & Kelly, C. S. (2018). Self- and social-regulation in type 1 diabetes management during late adolescence and emerging adulthood. *Current Diabetes Reports*, 18(5), 23. <https://doi.org/10.1007/s11892-018-0995-3>.
- Zarrett, N., & Eccles, J. (2006). The passage to adulthood: Challenges of late adolescence. *New Directions for Youth Development*, 2006(111), 13–28.