


# Parental Stress as a Child With Diabetes Transitions From Adolescence to Emerging Adulthood

Journal of Patient Experience  
2020, Vol. 7(3) 365-371  
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DOI: 10.1177/2374373519842963  
journals.sagepub.com/home/jpx  


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## Abstract

This study examined parental and caregiver distress among families caring for children with type 1 diabetes as the child transitions into Emerging Adulthood. More than 96 hours of semistructured interviews were conducted with 19 adult caregivers including parents, grandparents, and other adult family members of 10 children. Each research partner participated in multiple face-to-face, 1- to 1.5-hour long-evolving interviews over the course of 4.5 years. Paradoxically, caregivers were found to experience significant increase in distress as their child with diabetes entered the developmental stage of Emerging Adulthood, 18 to 25 years old, by which time they should be masters of self-care, and parental distress should begin to decline. This increase in familial distress was associated with the emerging adults leaving the home, being unable to maintain an acceptable level of self-care, and experiencing declining health, frequent visits to the emergency department, and repeated hospitalizations. These findings suggest that parental distress from caring for a child with diabetes continues as the child ages, matures, and transitions into adulthood and may be exacerbated when the emerging adult with type 1 diabetes leaves the home and the direct observation and care of the parent.

## Keywords

diabetes, parental caregiving, caregiving stress, Emerging Adulthood

## Introduction

Diabetes management issues and parental caregiver distress are well studied among parents caring for young children and adolescents with type 1 diabetes (T1D). Whittemore et al (1) found widespread parental psychological distress at the time their child was diagnosed with T1D. This stress was reduced, but still significant, 1 to 4 years after diagnosis. As the child with diabetes (CWD) ages and develops into adolescence, diabetes management and control may begin to lapse, resulting in increased risk of medical complications for the child (2). This is a period of great variability in child self-care, glycemic control, and caregiver distress complicated by multiple factors related to the effects of individual differences in normative psychosocial, cognitive, and sexual development during adolescence (3).

Until recently, little attention was given to care management and related psychosocial challenges of living with diabetes as adolescents transition into young adulthood. Arnett (4) distinguished the period of Emerging Adulthood (EA) as

being between the ages of 18 and 25. The American Diabetes Association recognized a dearth in empirical evidence on the best approaches to describe and address this transitional period, calling for a closer look at the obstacles faced by young adults living with diabetes (5). Specifically, it was noted that the period of EA is typically rife with gaps in care causing numerous associated problems including lack of accessing health care, deteriorating glycemic control, increased occurrence of acute complications, emergence of

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chronic complications of diabetes, and psychosocial, behavioral, and emotional challenges.

A few studies have since focused on better understanding and addressing the challenges faced by this population of patients. Even fewer have acknowledged the parental distress that continues to plague their parents, which can lead to mental and emotional exhaustion (6). As a means to better understand the variable stress levels in parental coping, this study aims to examine the lived experience of parents of a CWD as they witness and struggle with their child's physiological and emotional development specifically during the period of their EA. For contrast, the caregiving experience of parents of an EA/T1D will be compared to that of parents of a younger CWD.

### *Transitioning From a Child to an Emerging Adult With T1D*

Blum et al (7) defined health-care transition as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems” (p. 570). This transition is especially important for EA with T1D due to the complexity of the disease and the need for daily self-care and medical decision-making (8,9). However, many struggle through this transition and do not receive consistent and appropriate care, which places them at increased risk of poor glycemic control (10). Garvey et al (11) found that 26% of respondents reported a gap of more than 6 months between the last pediatric diabetes visit and the first adult visit, and 6% reported a gap of more than 12 months. Those who cited moving or relocation as the most important reason for transition were significantly more likely to experience gaps between pediatric and adult care of more than 6 months. This suggests additional consequences for EAs/T1D leaving home to attend college or simply to assert their independence from their parents and finding themselves without well-established parental care reminders.

This transitional period also brings psychosocial challenges for EAs/T1D. Northam et al (12) found that EAs/T1D report higher levels of psychiatric morbidity and lower school completion rates than their nondiabetic peers. Furthermore, psychiatric morbidity was associated with poor metabolic control and failure to transition to adult diabetes care. Wilson (13) found that college students experienced difficulties managing their diabetes due to scheduling and time constraints, which interfered with testing blood glucose, eating glycemic loading snacks, and injecting insulin during the day. Students perceived that they did not receive adequate support from college or university personnel to balance the demands of coursework and disease management. College students with T1D also report that they struggled with maintaining a diet promoting blood glucose management due to living conditions, such as life in a dormitory, financial challenges, and finding the time necessary to prepare healthful meals (14).

Some T1D college students reported purposeful reduction in insulin volume so that blood glucose levels (BGLs) would

be slightly elevated, or “run high” (13, p. 26). This hyperglycemic strategy was intended to prevent a hypoglycemic incident and avoids possible loss of concentration or consciousness, and even loss of friends who may feel uncomfortable by unusual behavior brought on by a low. Elevated hemoglobin A<sub>1C</sub> is known to be associated with serious long-term microvascular and cardiovascular complications (15) that college students may dismiss, or not know about, since these effects are not immediately experienced.

Parental influence and parent/child relationships have been found to have an effect on self-care behavior and glycemic control of EAs/T1D. Gillibrand and Stevenson (16) reported that strong family support was the best predictor of good self-care among a number of psychosocial variables for 16 to 26 year olds with T1D. However, there seems to be a delicate balance between parental support and parental control. Helgeson et al (17) found that parental control was associated with an increase in depressive symptoms, whereas parental support was associated with a decrease in depressive symptoms and perceived stress for the EA/T1D. Parental support was also related to better self-care behavior, but not to glycemic control. The reaction of EAs/T1D to parental support may depend on their perception of support versus control. Some parents may choose to take a “back seat” in their child's T1D management, while others continue to treat their college student as a “fragile child” and have difficulties letting go and allowing for their child's independence in self-care to develop (18).

There is ample evidence that EAs/T1D struggle with disease management and the biopsychosocial consequences of their self-care behavior. The behavior of parents during this transition varies, although the relationship between parents and their EA is a significant predictor of the child's self-care and health outcomes. What is not known, and has not been well studied, is the extent of emotional distress that the parents experience during this time.

### **Method**

This study used a mixed inductive–deductive qualitative research design and the Cultural Construction of Disease Model (19,20) with specificity to eliciting cognitive and behavioral categories of distress due to caregiving of a CWD. To develop the conceptual and behavioral categories of interest for examination in this study, research partners (RPs) were asked to participate in the technique of Free Listing in which each respondent was asked to list all the types of distress in parental caregiving of a CWD (21). This produced an initial list of types of distress categories and terminology used by respondents to describe them. The results from the free listing, literature review, and models providing analytic frameworks for cultural construction of disease and parental stress were then incorporated to develop a set of 127 respondent-derived and theoretically derived cognitive and behavioral categories of interest. The categories of interest were given clear definitions and were used

to construct questionnaires to elicit relevant information via semistructured interviews which were digitally recorded. The recorded interviews were transcribed and analyzed using QDA Miner, a qualitative analysis software package, to examine differences in psychological states and patterns of stress between caregivers of an EA and caregivers of a younger CWD.

Intensity sampling was used to include experiential experts, that is, persons who have lived the caregiving experience (22). In this study, experiential experts were parents, grandparents, and other family members who have experienced caregiving of a child with T1D. Research partners were recruited through personal solicitations by a Choctaw tribal member who worked for the project, lived in the general geographic region, and was familiar with the communities populated by other Choctaw tribal members.

Over the course of 4½ years, 19 RPs were interviewed at intervals ranging from every 3 to 10 months in order to capture the potential for change in their parent–child experiences, perceptions, and behaviors longitudinally. The primary interview locations included tribal clinics, homes, or other places convenient for the participants. This research was conducted by collaborating with 10 families in the Choctaw Nation of Oklahoma resulting in 79 semistructured interviews yielding approximately 96 hours of interview data. Research partners provided detailed and dense information specifically relevant to each family’s experience with diabetes. This created a deep and rich data bank showing the evolution of caregiving, coping, and changing types of distress as defined by the parents and other family caregivers in real time.

In terms of acculturation dynamics (23,24), contemporary American Indian culture is best characterized as highly heterogeneous (25,26). The expressions of cultural heterogeneity among these particular RPs can be mainly characterized as highly acculturated or “mainstream positive” (27). This assessment is the product of the research team’s repetitive on-site, interpersonal interviews, discussions, queries, and empirical observations of these RP’s in situ. These ethnographic data reveal that they do not participate in the native language, native foods, native annual cycle ceremonies, or native religious beliefs and practices. Contrary to traditional Choctaw life ways, they are English-only speakers, have an American dietary pattern, and participate in Christian Protestant religious beliefs and practices. Their world view is very largely consistent with that of mainstream white American culture in values, beliefs, and behaviors. Nonetheless, they are, in fact, proud American Indian tribal members. Further, it would be wrong to conceptualize them or their behavior as uniquely American Indian or representative of any or all contemporary American Indian people.

Five families with 11 participating caregivers, including 6 parents, 4 grandparents, and 1 aunt, cared for a CWD transitioning into EA. The remaining 5 families in the research pool cared for a younger CWD and included 8 participating

**Table 1.** Demographic Data.<sup>a</sup>

Social Characteristics	EA/T1D	CWD
Participating families	5	5
Caregivers interviewed	11	8
Parents	6	5
Grandparents	4	3
Other	1 (Aunt)	0
Average age of child	19.2 years	10.8 years
Average years since child was diagnosed	10.0 years	6.2 years
Education level of child		
Preschool	0	1
Middle school	0	2
High school	2	2
College (none currently attending)	3	0

Abbreviations: CWD, child with diabetes; EA, Emerging Adulthood; T1D, type 1 diabetes.

<sup>a</sup>These data reflect demographics at the conclusion of the 4.5-year study.

caregivers, 5 parents and 3 grandparents. See Table 1 for demographic data.

Caregivers reported emotional distress in 27 categories of interest specifically related to psychological functioning. As shown in Figure 1, reports of cumulative distress from these 27 categories increased dramatically as the CWD entered EA, which is most pronounced at age of 18. Data analysis by QDA software indicated caregivers of an EA/T1D experience certain types of distress more frequently than caregivers of a younger CWD. The text of each interview was closely examined within predetermined categories of interest to better understand the stressors experienced by these caregivers.

## Results

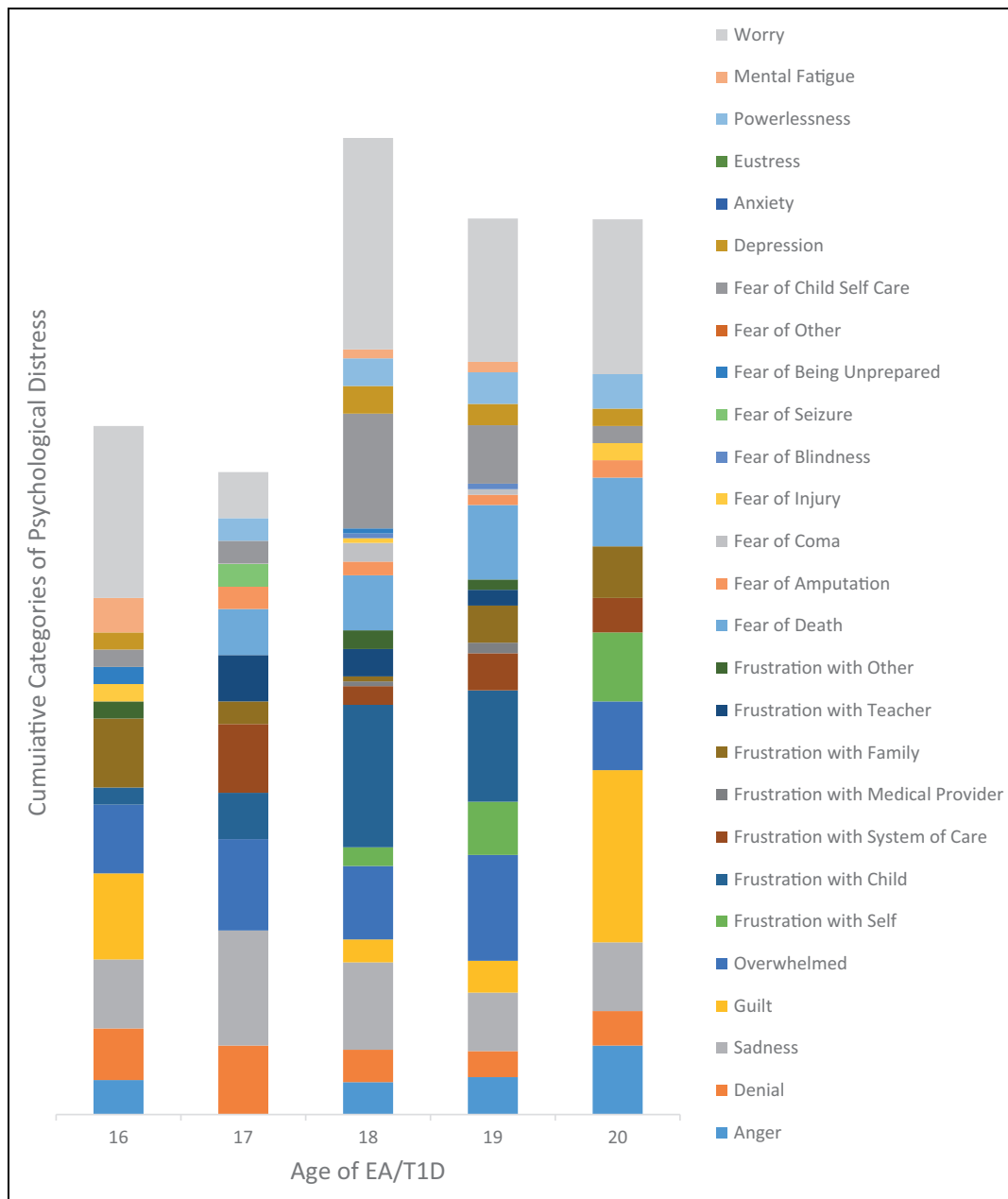
Caregivers of EA/T1D more frequently reported feeling overwhelmed and powerless and discussed being in denial as a coping mechanism.

*Mother: He is my baby. It’s just being Mom. Letting him go is a big deal. I can’t control him anymore. When he was a kid I could. I could do more for him when he was smaller, about his eating habits and everything, but now that he is older, I can’t control that. I haven’t stopped thinking about it. Is everything okay? What is he not telling us?*

Caregivers of EA/T1D discussed being frustrated with their child and with themselves more than caregivers of a younger CWD.

*Mother: Even though she is 18, I don’t feel like she is mature enough to be out there on her own. I get frustrated with her over that. I tell her, “You don’t take care of yourself. You don’t take care of the dog. How do you expect to live on your own?”*

Caregivers of EA/T1D more frequently expressed fears that the EA was not practicing appropriate self-care and that the EA would experience premature death.



**Figure 1.** Cumulative categories of psychological distress experienced by caregivers as their child with diabetes (CWD) transitions into Emerging Adulthood/type 1 diabetes (EA/T1D).

*Mother: I guess my concern would be, because she is not taking care of herself, how long is she going to live. I told her, if you don't take care of yourself, you're shortening your life. I feel like my daughter is not going to live that long if she doesn't take care of herself. I am just tired of her hurting herself.*

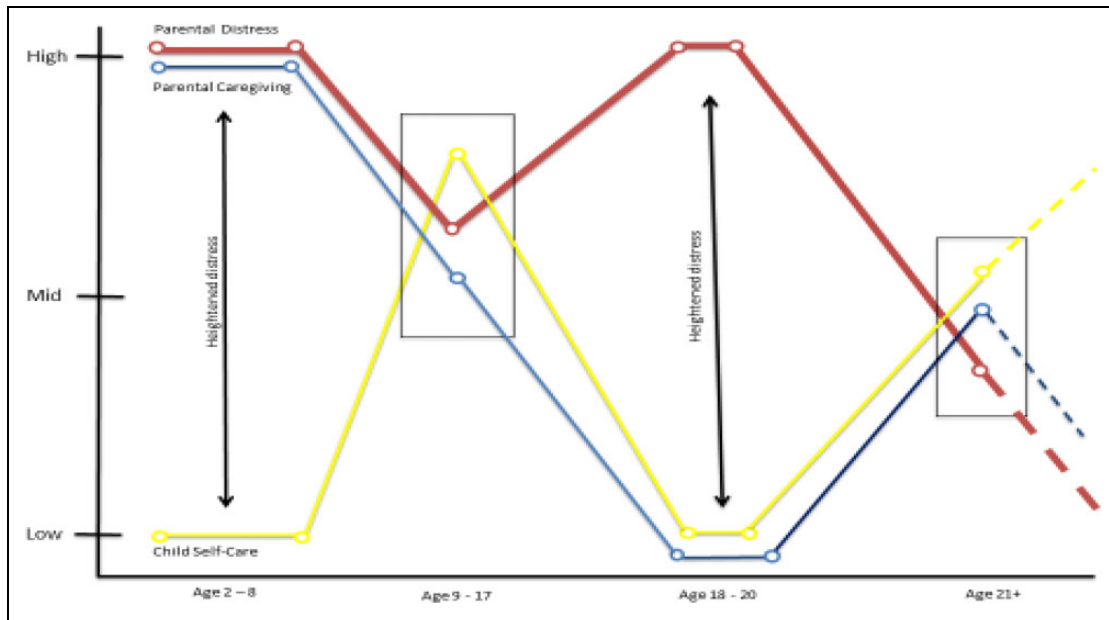
There were also heightened concerns that the EA was not complying with medication regimens and adequately controlling BGLs.

*Mother: Well, him being 19, you know, he's thinking that he's on his own and he tries to take care of himself so he doesn't have to tell Mom he's going to the ER. You know, I find out*

*later. He can't keep going to the ER. He just can't keep doing that. That's not a fixer. I think he thinks, if he gets there and they keep giving him fluids to keep him rehydrated, that's a fixer. That's not a fixer.*

## Discussion

Although this study is limited by a small sample size, we recognized a distinguishable pattern of distress which these parents and family caregivers experienced, and we propose that other parents and caregivers are likely to experience similar patterns of distress as the CWD ages and transitions



**Figure 2.** Parental caregiving distress varies across the aging and developmental process of the child with diabetes (CWD) with heightened periods of distress near the time of diagnosis, and during emerging adulthood, and periods of reduced, but greatly variable, stress during childhood and mature adulthood.

into EA (see Figure 2). The EAs/T1D in this study left their parents' homes after completing high school. Two EAs/T1D enrolled in college and attempted to hold down part-time jobs, while others moved out of the home and began working full time. Parents and caregivers watched as their EA/T1D failed to appropriately manage their diabetes and take care of themselves, exhibited suboptimal glycemic control, and made repeated visits to the emergency department. One EA became very ill to the point of near kidney failure and required multiple extended hospital stays.

At the time of diagnosis, regardless of the age of the child, parents experience a period of heightened distress as they likely face near death experiences, hospital stays, and extreme fluctuations in the child's blood glucose levels (BGLs). During this time, the parent is so entrenched in caregiving that they may experience diabetes by proxy (28). This condition occurs in parents whose constant vigilance and heightened state of anxiety are enacted toward the CWD with such intensity that parents come to a kind of pseudo-embodiment of their child's condition. Although the parents do not have the actual condition, their constant and extremely close scrutiny of their child's physiological and behavioral states renders them virtual cases as well. Although this parental caregiving strategy may be considered a coping mechanism for the parent, and typically will benefit the child, a constant state of hypervigilance may eventually cause more distress for the parent and actually be maladaptive.

As the CWD ages and matures into adolescence, they are likely to take on more responsibility for self-care and the parents' caregiving role should decrease. However, this is a period of great variability. The first box on the timeline in

Figure 2, around the proposed levels where these categories of care and distress may fall, indicates this variability. Parental distress as the CWD experiences adolescence is dependent upon several factors that influence the ability and willingness of the child to manage insulin intake, exercise, and diet and ultimately maintain a reasonable level of glycemic control. Lancaster et al (29) reported that glycemic control often suffers during this period due to disagreements between the CWD and the parent regarding treatment responsibilities. If the adolescent adheres to a treatment regimen and maintains glycemic control, the parents' stress level is likely to be lower than that of a parent dealing with a CWD who is unwilling and/or unable to be responsible for, and successfully manage, their BGLs.

Paradoxically, as the adolescent moves into EA, their self-care may decline even more. At this point, the parent is likely to have relinquished all responsibilities for caregiving and disease management to the EA/T1D, particularly if the child leaves the parental home. As with the 5 families caring for an EA/T1D in this study, the child may experience a significant decrease in glycemic control. Consequently, the parents experience another period of heightened distress as they once again face similar circumstances that occurred early after diagnosis, such as hospital stays and fears that their child will die from complications of T1D.

After some period of experiencing increased T1D complications and deteriorating health, the EA/T1D may return to the parental home, at least temporarily, while they attempt to regain control of and stabilize their BGLs. This is also a period of great variability in parental distress, parental responsibility for caregiving, and child self-care. This is indicated by the second box on the timeline in Figure 2.

Again, the parents' stress is largely dependent upon the EA/T1D's ability and willingness to maintain glycemic control and good health. The parents and the EA/T1D may renegotiate caregiving responsibilities. Parents may reclaim some control over the EAs/T1D insulin intake and diet, as well as other health-related behaviors. For example, in order to ensure that the EA/T1D gets enough rest, the parents may establish a curfew that would hopefully dissuade them from staying out late at night.

Eventually, a new balance of caregiving responsibilities should be achieved where the EA/T1D is again primarily responsible for their own disease management. The parents' caregiving responsibilities should again decrease. However, the parents may be available to assist when needed. Ideally, the EA/T1D will continue to mature, improve their self-care skills, and achieve reasonable glycemic control. At this point, the parents may once again experience a lower and more manageable level of parental caregiving distress.

The stress levels of parents and other family caregivers in this study were directly related to the health status of the EA. When the EAs/T1D were living outside the parental home and their health was at risk, their caregivers experienced significant increase in worry and distress. When the EAs/T1D moved back home with their parents and caregivers were able to provide hands-on care and help the EA regulate their BGLs and symptoms of diabetes, the EAs/T1D overall health improved and caregiver distress diminished.

The EAs/T1D in this study demonstrated behaviors that have been recognized as typical in previous studies of this population. Their self-care declined and their physical health suffered greatly. However, our findings show that the effects of their behavior are not only detrimental to the diabetic patient but also to their parents and other family caregivers. Just as previous studies with T1D adolescents and their caregivers have provided information to prepare parents for this developmental period, and the possible turmoil that is likely to occur with their adolescent CWD, health-care providers, particularly mental health providers, should be aware of the recognized behavioral patterns and reduced self-care during the development period of EA and help prepare parents of EAs/T1D for yet another period of increased caregiving challenges and emotional distress.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was supported by a grant from the National Institute on Minority Health and Health Disparities, grant award number P20MD000528.

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