



Financial Barriers in Emerging Adults With Type 1 Diabetes: A Qualitative Analysis

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BACKGROUND | Emerging adulthood is a period fraught with challenging life transitions for many and is especially difficult for individuals with type 1 diabetes, as they encounter more obstacles to independently managing their diabetes. We examined the barriers faced by emerging adults and parents of emerging adults with type 1 diabetes and the impact these barriers had on their lives.

METHODS | Emerging adults and parents of emerging adults with type 1 diabetes were recruited from primary care and specialty clinics and via social media posts. In the parent study, semi-structured interviews were conducted to understand what supported and did not support diabetes self-management. Interviews were transcribed, coded, and analyzed for common themes. This sub-analysis analyzed data related to financial challenges in accessing diabetes management equipment and supplies.

RESULTS | This study included emerging adults with type 1 diabetes ($n = 33$; mean age 20 ± 2.9 years) and parents of emerging adults with type 1 diabetes ($n = 17$; mean age 47.5 ± 6.9 years). The majority of emerging adults used an insulin pump and continuous glucose monitoring system ($n = 24$ [73%]). Four main themes emerged related to access to care: 1) affordability of diabetes management tools, 2) managing insurance, 3) communication with pharmacies and health care providers, and 4) emotional consequences of financial stress.

CONCLUSION | The current health system is challenging for emerging adults with type 1 diabetes and parents and is causing substantial emotional and financial stress. Future research is needed to address interventions for helping emerging adults and their parents navigate the cost of living with diabetes.

Emerging adulthood is a critical period when those with type 1 diabetes independently manage diabetes and navigate the health care system for the first time. Self-management of type 1 diabetes during emerging adulthood is complicated by emotional instability and many life transitions while learning to balance academic, career, economic, social, and family priorities (1). Emerging adults who endure these competing demands often have difficulty prioritizing diabetes self-management. During emerging adulthood, lapses in diabetes care often present in addition to suboptimal glycemic outcomes, increased prevalence of acute complications, emergence of long-term complications, and mental health comorbidities (2). Notably, <14% of emerging adults with type 1 diabetes meet the American Diabetes Association's general glycemic management goal of A1C <7% (3).

Emerging adults with type 1 diabetes require insulin, testing supplies, syringes or pen needles, and treatment for hypoglycemia (e.g., glucose tablets, juice boxes, snacks, and glucagon).

Other supplies that may improve quality of life, such as a continuous glucose monitoring (CGM) system or an insulin pump, come at an extra expense. Diabetes medications and supplies can be accessed through local and mail-order pharmacies and durable medical equipment (DME) suppliers; however, each insurance company may have different policies regarding what is covered and what is considered DME or prescriptions. One in four insulin users ration their insulin because of cost (4), which can lead to hyperglycemic complications later in life. Emerging adults may be more vulnerable to rationing insulin and financial stress (5). The inability to afford diabetes care has increased to the point where some emerging adults are rationing or seeking alternative sources (e.g., black market) to access what they need to survive (6).

Parental support is important during the emerging adult period. However, a barrier to increasing parental support is that emerging adults strive to become independent from their

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parents. Parents can provide support for diabetes self-management tasks and mental well-being (7). Yet, if emerging adults do not have independent means to afford diabetes care and are unable to obtain financial support from their parents, detrimental effects may occur. Although supplies and medications comprise the bulk of the financial burden for people with diabetes, costs of health care provider (HCP) visits (e.g., copayments) often add to the financial stress. Most insurance providers have a higher copayment requirement for visiting an endocrinologist compared with a primary care provider. Because of the higher cost, some individuals may seek care from a primary care provider even though there may be a knowledge disparity about the management of type 1 diabetes between primary and specialty providers. Health insurance premiums vary but can be very costly with complicated plans and hard-to-reach deductibles. Given the dearth of research focused on emerging adults and diabetes-related costs, the purpose of this qualitative study was to understand the financial challenges emerging adults with type 1 diabetes face in accessing diabetes management equipment and supplies.

Research Design and Methods

Overview

We used a qualitative thematic approach to analyze interviews with emerging adults and parents of emerging adults. Interviews were conducted to assess needs to achieve target A1C levels. This study was approved by the University of Utah Ethics Review Board (IRB #00126057).

Recruitment

Emerging adults with type 1 diabetes and parents of emerging adults with type 1 diabetes were recruited by contacting endocrinology and primary care clinics and through social media posts to a private online group for people with type 1 diabetes. Emerging adults who wished to participate were included if they were 1) 16–25 years of age, 2) diagnosed with type 1 diabetes, 3) receiving care for type 1 diabetes, and 4) able to read and speak English. Parents who wished to participate were included if they 1) had a child aged 16–25 years with type 1 diabetes who was receiving care and 2) were able to read and speak English. Both emerging adults and parents of emerging adults were excluded if they were unable to read and speak English.

Procedures

Emerging adults and parents of emerging adults were interviewed by telephone. Interviews were conducted by a male trained research assistant with type 1 diabetes (E.G.G.). Individual

interviews focused on what supported and did not support diabetes self-management and what interventions they perceived would be helpful for themselves or others with type 1 diabetes in their age-group. Each interview lasted on average 30 minutes. There was no prior relationship between participants and the research team. No participants discontinued participation. A semi-structured interview guide (Table 1) was developed and pilot-tested on an emerging adult before use. All interviews were audio-recorded, transcribed verbatim, and verified for accuracy without being returned to the participants for additional comments. No repeat interviews were conducted.

Data Analysis

A sub-analysis of the data were conducted, extracting text specific to access and affordability of diabetes medications and supplies. Using principles of qualitative thematic analysis (8,9), we coded data using NVivo, v. 11 (10). First, the authors (E.G.G., M.L.L., and M.E.P.) coded three emerging adult interviews to develop the initial codebook. The authors coded the remaining adult and parent interviews in pairs or individually using the codebook. Using an open coding approach, new codes were added on an ad hoc basis (8). Codes were compared, contrasted, and collapsed to develop corresponding themes (11,12).

Results

Participant Characteristics

Participants were 33 emerging adults with type 1 diabetes and 17 parents of emerging adults with type 1 diabetes. The mean age of emerging adults was 20.1 ± 2.9 years, and the mean age of parents was 47.5 ± 6.9 years. Participants were overwhelmingly White (90% for emerging adults and 94% for parents); therefore, results are representative of the White experience. The majority of the emerging adults were using a CGM system and insulin pump ($n = 24$ [73%]). Additional demographic details are shown in Table 2.

Themes

Four themes emerged from the data: 1) affordability of diabetes management tools, 2) managing insurance, 3) communication with pharmacies and HCPs, and 4) emotional consequences of financial stress. Below we provide excerpts from the interviews to illustrate the important themes.

Affordability of Diabetes Management Tools

Participants had mixed ability to afford their diabetes management tools. Many emerging adults indicated that, even with insurance, the high cost of diabetes management tools

TABLE 1 Interview Guide

| Resources | |
|---|--|
| What resources are you currently using? | |
| Family | Describe how that support comes about (e.g., Do you ask for support? Does the person ask you what he or she can do?) and how you access the person (e.g., in person, text message, social media). |
| Romantic partner | Describe how that support comes about (e.g., Do you ask for support? Does the person ask you what he or she can do?) and how you access the person (e.g., in person, text message, social media). |
| Friends | Describe how that support comes about (e.g., Do you ask for support? Does the person ask you what he or she can do?) and how you access the person (e.g., in person, text message, social media). |
| Health care provider | Describe how this support comes about (e.g., prescriptions only, education, counseling) and how you access the person (e.g., in person, medical record messaging, phone). |
| Technology | Apps, insulin pumps, sensors, telehealth |
| Information | Websites, online communities |
| What gets in the way of accessing diabetes resources? Time Lack of interest Not knowing where to get resources Resources not available (e.g., I'm not around the person. I cannot afford technology.) I don't need resources (if this is selected, ask why) | |
| Imagine you could design the perfect system for you to manage your diabetes. What things would be helpful to have? What resources would be in the perfect system? (if they mentioned technology) If these diabetes resources existed, how helpful would these be for you? Integrative team (counselor, diabetes educator) Video-based telehealth visit Messaging system with health care providers Text-messaging from friends or family (maybe someone whose job it is to answer these messages) Peer support program (with others who also have type 1 diabetes) outside of a clinic setting Shared medical visits with peers or people who also have type 1 diabetes | |
| Specific training on: | <ul style="list-style-type: none"> ● Troubleshooting glucose levels, diabetes devices, etc. ● How to deal with day-to-day situations (school, work, fitness, diet) ● How to deal with prescriptions and insurance (talking with insurance company, picking up prescriptions) ● How to manage diabetes costs (insulin, CGM supplies, pump supplies) |
| Managing Life With Diabetes | |
| Tell us who manages the challenges around your health insurance. Completely on your own With someone else (Who is that? How and why are they helping?) | |
| Tell us who manages the challenges around health care provider visits. Completely on your own With someone else (Who is that? How and why are they helping?) | |
| Tell us who manages the challenges around health care prescriptions. Completely on your own With someone else (Who is that? How and why are they helping?) | |
| How do you manage challenges at school and/or work in relation to diabetes? Who handles those challenges? Does anyone help you (e.g., a parent)? Why do they help you? | |
| How do you manage challenges related to family and friends in relation to diabetes? What about social situations, such as a party (food, alcohol, etc.)? | |
| Would you be willing to share your A1C? If so, what is your A1C? | |
| Is there anything else you would like to tell us about diabetes that we haven't already asked? | |

TABLE 2 Demographics

| Variable | Emerging Adults (n = 33) | Parents (n = 17) |
|---------------------------------------|--------------------------|------------------|
| Age, years | 20.1 ± 2.9 | 47.5 ± 6.9 |
| Diabetes duration, years | 8.5 ± 5.2 | — |
| Age at diagnosis, years | 11.5 ± 5.4 | — |
| Sex | | |
| Female | 19 (58) | 13 (76) |
| Male | 14 (42) | 4 (24) |
| Race | | |
| White | 30 (90) | 16 (94) |
| Asian | 1 (3) | — |
| Black or African American | 1 (3) | — |
| Other | 1 (3) | 1 (6) |
| Relationship status | | |
| Single | 19 (58) | 1 (6) |
| Married | 7 (21) | 16 (94) |
| Relationship, <3 months, not married | 1 (3) | — |
| Relationship 3-12 months, not married | 2 (6) | — |
| Relationship >1 year, not married | 4 (12) | — |
| Living setting | | |
| Suburban | 23 (70) | 13 (76) |
| Urban | 3 (9) | — |
| Rural | 7 (21) | 4 (24) |
| Education level | | |
| High school | 10 (30) | 1 (6) |
| Some college | 20 (61) | 9 (53) |
| Bachelor's degree | 3 (9) | 3 (18) |
| Master's degree | — | 3 (18) |
| Doctorate degree | — | 1 (6) |
| Sexual orientation | | |
| Heterosexual | 24 (73) | — |
| Bisexual | 3 (9) | — |
| Pansexual | 1 (3) | — |
| Unknown | 5 (15) | — |
| Health insurance | | |
| Employer-based | 23 (70) | — |
| Private pay | 3 (9) | — |
| Medicaid | 3 (9) | — |
| Military | 1 (3) | — |
| Other | 3 (9) | — |
| Technology use | | |
| Only pump | 1 (3) | — |
| Only CGM | 4 (12) | — |
| Both | 24 (73) | — |
| Neither | 4 (12) | — |

Data are mean ± SD or n (%).

prevented them from easily obtaining insulin and diabetes technology (e.g., an insulin pump or CGM system). When discussing concerns about affordable insulin, one emerging adult stated, “It was actually cheaper for us to go to Mexico and pick up insulin from the pharmacies in Mexico and drive back to Utah” (female, 20 years of age).

Besides the basic necessity of insulin, other diabetes management tools may be out of reach to emerging adults due to cost. One emerging adult stated, “The supplies are incredibly expensive. My CGM has been really nice, but I’m

probably going to have to change CGM [systems] because we’re not really able to afford this one” (male, 23 years of age). Another emerging adult stated, “As far as technology goes, money would be [a] problem. That’s why it took me so long to get a CGM and why I still don’t even have a pump yet. Working through insurance can be frustrating and difficult” (male, 22 years of age).

Several emerging adult participants were still on their parents’ insurance plans, which eased financial worries and allowed them to access their desired diabetes management tools. A

parent of an emerging adult stated, “We have great insurance so as far as technology. She’s got what she wants right now” (female parent, 61 years of age). One college student explained that affordability was not a concern at the moment, stating, “I’m still on my parents’ insurance. My dad’s got pretty good insurance through his work, so I’ll just stay on until I’m out of college” (male, 22 years of age). However, emerging adults expressed worries about future insurance coverage. One emerging adult stated, “We’re all pretty scared for once we’re off, like, parents’ insurance. Once we are on our own, we don’t really know what to expect” (female, 20 years of age).

Managing Insurance

Emerging adults and parents alike had challenges understanding their insurance and coverage for type 1 diabetes medications and supplies. Nuances in pharmaceutical and DME benefits were confusing. There were also sudden changes in what was covered (e.g., insulin brands), resulting in frustrations. As one parent stated:

“I feel like it’s very hard to understand insurance. One minute, her prescriptions, like, for her insulin and stuff, is considered a prescription, and so it goes toward deductible, and then this last year they switched it, and they’ve made it more like a durable medical, and so nothing goes toward deductible. It just stays the same every month. So even once deductible is met, we’re still paying, you know, the same amount. So, yes, I feel like insurance could get easier.” (female, 52 years of age)

The time required for emerging adults to continuously navigate systems of insurance companies, pharmacies, and HCPs was described as an ongoing challenge. Frustration regarding the time spent managing insurance was prevalent among participants. One emerging adult stated, “Every time I do a re-up on my pump, they always deny it the first two times because they say that they don’t cover it, even though I’ve had this same insurance company the last 3 years” (male, 19 years of age). Another emerging adult recounted that “health insurance really fights us on a lot of things. We fought with them for 6 months to cover my initial diagnosis hospital stay” (female, 16 years of age).

This time burden also affects parents of emerging adults. The majority of emerging adult participants indicated that parents regularly assist them in managing insurance needs. Parents described having to make frequent calls, taking up hours out of their day. One parent of an emerging adult stated, “You always have to be calling either your medical equipment company or insurances. It takes time. And you just don’t have that time.” (female, 23 years of age)

Communication With Pharmacies and HCPs

In addition to contacting insurance companies, time was also spent working with pharmacies and HCP offices. Emerging adults reported challenges in managing multiple systems when trying to get diabetes medications and supplies. One emerging adult stated, “There’s that time of waiting on the phone to get ahold of a pharmacy tech or to talk to your doctor about sending a new prescription. I wish that there was a way I could just submit a request online” (female, 23 years of age). When discussing time spent contacting HCPs, one emerging adult stated, “That can be a struggle, because sometimes we play phone tag just trying to get time that works for both of us” (female, age 19 years). These challenges sometimes result in lapses in filling prescriptions, including diabetes technology (e.g., CGM sensors and pump supplies) and insulin. Participants were interested in learning strategies to better coordinate with pharmacies and HCP offices.

Lapses in communication between insurance companies, pharmacies, supply companies, HCPs, and patients make it difficult for emerging adults to maintain sufficient stores of diabetes management supplies. Emerging adults must then spend additional time navigating these problems. One emerging adult stated, “I always seem to have trouble when it comes to having to order new supplies. It’s so hard with my insurance sometimes to get the right stuff at the right time” (male, 22 years of age). Coordination of these entities was especially challenging as described by one participant:

“I’ve had issues with just keeping a good supply of [diabetes management supplies]. I request my supplies, and they don’t send them for a while, and then I run out, or I have to wait to pick up prescriptions from the doctor while waiting for the insurance company to make sure it can go through. The timing and communication between insurance, supply companies, and the doctor’s office is the biggest issue I’ve experienced.” (male, 24 years of age)

Other challenges were related to the need for multiple diabetes-related prescriptions that are not always filled simultaneously or that require frequent refills (e.g., monthly versus every 3 months). As one parent described, “Trying to get prescriptions is a pain in the butt. You know, like, this is something that, obviously, they’ve got to have . . . to live. I don’t understand why we have to do refills every time we turn around, you know? So, to me, that is a huge barrier” (female parent, 52 years of age).

Emotional Consequences of Financial Stress

Both emerging adults and the parents expressed emotional distress regarding overall diabetes financial costs and working with insurance on finding affordable supplies. As one parent stated, “The frustration is the overwhelming cost and the price gouging of insulin. Our insurance company gets all the prescriptions for insulin through Canada because it’s so much less expensive, and I just think that’s ridiculous” (female parent, 51 years of age). Occasionally, emerging adults said they fear that they will not receive their supplies in a timely manner because of financial issues, resulting in serious complications. One emerging adult noted, “It’s really obnoxious. And, you know, time is money, and time is scary. Sometimes, diabetics don’t have that kind of time to get their supplies” (male, 19 years of age).

Emerging adults and parents indicated spending a lot of time on the phone with insurance to understand financial coverage and how much to pay for supplies, in addition to provider visits, which becomes overwhelming. As one parent of an emerging adult described her experience dealing with insurance, “I was able to really fight it. For other people, I could see not being able to fight, and just [being] like, ‘Oh, I guess I have to pay this much money,’ when it’s just the insurance trying to pull one over on us” (female, 42 years of age). Dealing with insurance companies was likened to a never-ending battle.

Emerging adults experience emotional distress as they begin to understand the financial burden that their parents have experienced when managing diabetes costs. As one parent stated:

“It wasn’t until she was older and would pay attention when we would go to the pharmacy to pick up things that she started noticing the costs. It took a toll on her, even as a young person, seeing what mom was spending on her diabetes. And she felt horrible. And it shouldn’t have. Even as adults, they shouldn’t have to. It just costs them so much.”
(female parent, 58 years of age)

In contrast, one emerging adult stated that she will worry about the costs of diabetes in the future, “When I turn 26 and get kicked off [my parents’ insurance], that’s when I will probably start to worry a lot” (female, 20 years of age). None of the participants were comfortable with how much they had to pay to manage diabetes, and yet they understood how vital it was to life.

Discussion

Our findings suggest that emerging adults with type 1 diabetes face several financial and time barriers that cause

emotional distress. These barriers include the inability to navigate finances, insurance, and obtain medications and supplies that can ultimately affect their diabetes management. Parents of emerging adults with type 1 diabetes are especially concerned about their child’s ability to manage these challenges alongside life transitions.

The cost of insulin and diabetes supplies is untenable for most emerging adults with type 1 diabetes. In this study, emerging adults relied heavily on their parents for insurance and financial assistance. Emerging adults, and the general population, often lack knowledge about their insurance because of ever-changing and complicated insurance coverage policies (e.g., coverage for various insulin brands or diabetes technology). Litchman et al. (6) found that those with health insurance still struggled to obtain medications and supplies because of high deductibles and extremely high copayment requirements. In our study, participants were obtaining insulin from other countries (e.g., Canada or Mexico) because of the high cost of insulin in the United States. Some states have enacted insulin copayment caps; however, no data exist to describe how these policies are influencing insulin rationing behaviors. Furthermore, these policies may not benefit individuals without insurance. Although emerging adults can stay on their parents’ health insurance plans until the age of 26 years, some may not have parents who have a family health insurance plan and therefore are challenged to obtain medications and supplies even earlier. Additionally, some Medicaid plans do not allow emerging adults >19 years of age or, in some cases, >21 years of age, to remain on their parents’ plan, causing additional stress to obtain insurance coverage (13).

Emerging adults must traverse several communication barriers to obtain the medication and supplies they need. These communication barriers include prescribing HCPs, pharmacies (sometimes multiple, such as local and mail-order services), DME companies, and insurance companies. Prescription delays can result from an overdue visit to the HCP (e.g., a lapse after transitioning from pediatric care, secondary to busy schedules, or because of an inability to pay the copayment), low stock at the pharmacy or DME company, delayed shipping from the pharmacy or DME company to the patient, and the need for prior authorizations. Efforts to develop systems that can simplify the communication process are needed.

Emerging adults face emotional consequences when they experience diabetes-related financial stress. Inability to access the tools needed to manage their diabetes can result in negative consequences such as complications (e.g., diabetic ketoacidosis, microvascular disease, or macrovascular disease),

hospitalizations, and missed school or work because of hypo- or hyperglycemia, all of which can be costly. Although Berg et al. (14) have shown that parent involvement is helpful during emerging adulthood, increased financial dependence on parents may result in parental financial distress and emerging adult guilt (6,15).

The current health care system is ineffective and cumbersome. As a result, it allows people to fail at managing their diabetes because of high costs, poor insurance coverage, and other financial barriers. Although some solutions to obtaining insulin exist (e.g., coupons, vouchers, and emergency fills), they are temporary, and many people are not eligible. Policymakers should use the results from this study and evidence from others addressing diabetes-related financial distress (4–6) to inform new policies that protect individuals with diabetes, including vulnerable populations such as emerging adults, from having to ration insulin.

Financial interventions are necessary to improve emerging adults' knowledge regarding how to navigate costs related to type 1 diabetes until policies change in the U.S. health care system. Emerging adults with other chronic conditions such as cancer also experience greater financial stress than the general population and express concern regarding medical costs and health insurance (16,17). Successful interventions to support emerging adult cancer survivors include financial education with HCPs, allowing open discussion about the cost of care and insurance coverage (18). An additional resource for emerging adult cancer survivors is the Samfund financial toolkit (19). These publicly available online videos are engaging and provide education about navigating health insurance and the costs of care to reduce financial stress (19).

Financial distress transfers from parent to child and may remain with the child during emerging adulthood. Noticing that parents are struggling with finances may lead to emerging adults believing that managing finances is a stressful process and to feel that they are unable to reach out to parents for financial support, which creates greater financial distress (20). Efforts to integrate education from HCPs and financial education resources into diabetes care and education are lacking. Future research should focus on developing and implementing such toolkits specific for emerging adults with type 1 diabetes and on addressing policy changes.

Certain limitations were present in this study. The sample primarily consisted of individuals who had parents who were emotionally and financially supportive. We may not have captured the experience of those with low parental support. Although our sample included rural, bisexual/pansexual, and

a few racially diverse participants, the majority of this sample is representative of White, suburban/urban, and heterosexual experiences. Historically, White individuals do not experience the medical racism that faces more racially and ethnically diverse individuals. Specifically, burdens, barriers, and acts of discrimination are less common for White individuals. Future research should seek to examine financial distress in racially and ethnically diverse emerging adults with type 1 diabetes.

Conclusion

This study contributes to the limited science on emerging adults with type 1 diabetes as it relates to financial distress. The current health care system is not set up to support emerging adults who must manage medical appointments, costly medications and supplies, pharmacies, DME companies, and complicated health insurance plans. Currently, there is a national effort to address the high cost of insulin. However, this is only one piece of a complex health care system that is inefficient and difficult for all people with diabetes to manage, and especially for emerging adults with diabetes. Future research should focus on developing and implementing financial toolkits and other resources to help emerging adults navigate the cost of living with diabetes.

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DUALITY OF INTEREST

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AUTHOR CONTRIBUTIONS

All of the authors wrote and reviewed/edited the manuscript. E.G.G., M.L.L., M.E.P., and N.A.A. researched the data. J.E.B. contributed to the introduction and discussion. E.G.G., M.L.L., and N.A.A. revised the manuscript. M.L.L. and N.A.A. are the guarantors of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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