

Highs and Lows and Type 1 Diabetes Mellitus

The Lived Experience of Young Adults with T1DM

Madeleine Ottignon, SN; Christina R. Whitehouse, PhD, CRNP, CDE; Melissa O'Connor, PhD, MBA, RN, FGSA

BACKGROUND

- Type 1 Diabetes Mellitus (T1DM) is a chronic autoimmune disease that affects the body's production of the hormone, insulin
- Current research on mental health and the impact of T1DM details conflicting quantitative research
- Understanding the impact of T1DM on mental health during adolescence may provide knowledge about the mental health needs of young adults with T1DM

AIM

To describe the lived experiences of young adults with T1DM and how it relates to their mental health status during adolescence

DESIGN

A qualitative explorative study using semi-structured interviews

METHODS

A convenience sample of 18 young adults with T1DM were recruited through social media (i.e. Instagram, Snapchat, and Facebook) and through an announcement in the monthly, national newsletter of the College Diabetes Network. Participants were interviewed individually via Apple Facetime and Google Hangouts. Professionally transcribed data were analyzed using thematic analysis

PATIENT CHARACTERISTICS (N = 18)

Age, Range	18-22	Age of T1DM Diagnosis, %	
Gender, n, (%)		<10 years old	33.3%
Female	16 (89%)	>10 years old	66.7%
Male	2 (11%)		
Ethnicity		Bachelors Degree	2 (11.1%)
Caucasian	12 (67%)	Some college	16 (88.9%)
African American	3 (17%)	Insulin Pump Use, %	15 (83.3%)
Asian	3 (17%)	Insulin Pen Use, %	3 (16.7%)

MAJOR THEMES

Lack of Proper Support

- From Family
- From Friends

“..somewhere in their head they do, but I don't think they care enough to fully grasp it, if that makes sense. Like they don't deal with it, so why should they put the effort into-- because it's not like they live in my house...” P3

“I know they were never like intentionally trying to be negative. Like none of it was said like – it was all said like with a joking attitude. I think it was – it lacked sympathy and empathy.” P7

Negative Mental Health Influence

- Stress
- Anxiety

“Your mental health probably affects your diabetes and your diabetes affects your mental health. And I would say life affects your diabetes and diabetes affects your life, you know.” P8

Isolation

- Intimacy with significant others
- Different then

“I was tired of people asking me, if I was shooting up heroin in the bathroom? Because I was on shots for a while.” P9

“it made me feel more different and I didn't want to feel different.” P1

Positive Personality Characteristics

- Responsibility
- Maturity

“Diabetes is always on your plate. If you want to be able to do other things, you have to be able to handle a lot going on.” P10

“I probably was a bit more responsible and mature than my friends. Literally, no one else is having to think about these things or a couple hours ahead. They are just thinking about right now and not in the future.” P11

FINDINGS

MAJOR THEMES

Negative Healthcare Provider Experiences

- Support
- Judgement

“They thought I was just being non-compliant. I wasn't being non-compliant for no reason. I was being non-compliant because I felt like I wasn't getting the help that I needed.” P6

“I didn't care about anything else, all I was concerned about was the bleeding in my eyes, and I was like, "Oh my god, I knew everything that was going to happen, but why did she have to tell me like that?" P3

Lack of Education

- Friends
- Participants

“I feel like my friends, they'll ask me questions about it every time, even now still. They'll still ask me questions about it. It's kind of like everything I've said a thousand times. So it's getting kind of annoying,” P2

I'm doing more research, and I'm like, "Oh my god, I can take a break from insulin pump." I didn't know that was a thing.” P3

Food

- Food binges
- Relationship with

“I would sometimes just like binge eat a bunch of carbs. Not that they were the ones that were really stopping me from doing that, but it was just a thing. Or just like go to a friend's house and eat a bunch of food that we normally wouldn't.” P6

“[Diabetes] just made me have a really bad relationship with food for a while. I think that really messes up everything when you have a bad relationship with food.” P2

CONCLUSION

This study generated major themes of isolation, negative healthcare provider experiences, and food impacts by participants. Many participants agreed that while they had support through family and friends, they felt they would best be reached by other people with T1DM. Participants also identified a lack of resources for managing T1DM in adolescence and a large amount of judgement from healthcare providers. This knowledge can assist healthcare professionals when caring for patients with T1DM through adolescence

ACKNOWLEDGEMENT

This research was supported by the Davis Family Undergraduate Summer Scholars Research Fund in the M. Louise Fitzpatrick College of Nursing