



2010

Getting High: An Inside Look into College Students' Lives with Type 1 Diabetes

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Recommended Citation

Spiewak, Amber 11, "Getting High: An Inside Look into College Students' Lives with Type 1 Diabetes" (2010).
Outstanding Ethnographic Research Projects. 2.
http://digitalcommons.iwu.edu/anth_ethno/2

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Getting High:

An Inside Look into College Students' Lives with Type 1 Diabetes

This is a presentation of an ethnographic study through visual media on the lives of college age students living with Type 1 Diabetes. Specifically with students at Illinois Wesleyan University who range in age from 18 to 21 years old. The participants are: Maddie Cross, 18 and a current first year student, Courtney Keenan who is 20 years old and a sophomore, and 21-year-old Ryan Quinn 21, a senior. All participants live on campus either in fraternity or sorority housing or in residence halls. Both Courtney and Ryan are from the Chicagoland area and Maddie is from Minneapolis, Minnesota. They found out they had Type 1 Diabetes at different times; Ryan and Courtney found out in middle school, and Maddie discovered her diabetes when she was a senior in high school. All three are involved with Sugar Free: IWU's Diabetes Action and Awareness Organization which was founded by Ryan, and does fundraising throughout the year for JDRF (Juvenile Diabetes Research Foundation). Both Courtney and Maddie are involved in a Greek Organization/ Sorority, Alpha Gamma Delta, whose main philanthropic endeavors are in support of diabetes awareness and education.

This photo-essay will be used to highlight specific areas about the group such as; the importance of distinguishing between Type 1 and Type 2 Diabetes for these students, the highs and lows of sustaining sugar levels, and the balance between their

college lives and managing their diabetes. All have proven important aspects of these three students' lives especially after reflecting on the difficulties during the ethnographic interview process. These students have felt that many do not understand what hardships they have had in dealing with their diabetes, compared to students living without the disorder and this photo-essay serves as a way for them to explain the hardships of living with diabetes and how it affects their lives.

Assumptions

Before conducting my research with this group of students I, as the ethnographer, had some assumptions about the group. In high school one of my good friends also had Type 1 Diabetes and the amount of work and stress put on her body was very excessive, to the point that she was not able to attend school regularly. I did not know how it was possible to handle transitioning leaving home for college for the first time and managing sugar levels and dealing with diabetes all at the same time. I did not understand how much time is needed to put in to managing diabetes for even one day. I only knew it was a lot of work and really hard to balance with other daily activities.

There has not been much research done on this community, specifically in college age students. The only real research I could find on the subject is with University students from the United Kingdom and while this research does give information regarding this group I wonder if there are major differences between students in the UK compared to the United States. In the research done by Myles Balfe the main focus is on routine and diets in university students with Type 1 Diabetes. This focus came about because of the interviews Balfe conducted with his respondents and the

information they gave to him about how they deal with their diabetes; especially in the context of developing their identity within the college atmosphere. In one of the articles written (Balfe, 2009 p.2370) he mentions that in the first year at University “self-care routines often slipped as they spent time getting to know their friends, staying up late, studying, going drinking and clubbing,” but that in the second year students “became increasingly concerned about achieving good diabetes control and routinizing their self-care practices.” Because of this research, I believed I would see a difference between the younger students and the older students and how they dealt with their diabetes management.

I also found it interesting that students he interviewed (Balfe, 2007b p. 141) were concerned about their health in the future and they were worried they would not live long. But, there were also some students he interviewed who felt that “you only live once ... you could die tomorrow” and they took bigger risks with their diabetes. I was interested to see how the Illinois Wesleyan students feel about taking risks and if they worry as much about their future as the UK students do. One of the main concerns of the students in Balfe’s studies (Balfe, 2007a p. 247) is that they do not want to be seen as

“abnormal” compared to other university students. From my interactions with the students, I do not anticipate that this will be something that impacts their lives because I did not see them as being “abnormal.” But, I am also interested as an ethnographer to see if their opinions differ from mine.

Methods

The ethnographic methods I used in my research were mainly group interviews with the participants. This, I believe, allowed them to feel more comfortable with opening up to the topic of their diabetes and made the conversation flow much easier. Ryan, Courtney, Maddie and I met four separate times to do group interviews together, ranging from an hour to two hours long in the Underground. The Underground is part of the Dugout at Illinois Wesleyan University, a quieter place in an area where many students pass through. The first part of the interviews focused on photographs that I asked the participants to bring to the in order to obtain information on their background, such as their home life and what things are important to them. I also asked them to bring photos that helped describe to them their life with diabetes, such as Courtney’s photograph from her Camp Counseling Diabetes Program, and Maddie’s photograph of her taking her blood sugar levels in her prom dress. From there I asked the participants interview questions such as “Could you walk me through your daily activities on how you handle your diabetes?” These questions usually led to more specific questions on answers I received from the them and also led in to other questions I had prepared before the interviews. One of the students usually stepped up as the first to respond to each question, but most answered at least some part of each



Figure 1: Courtney demonstrating to the me how to use the pump that distributes insulin to the body.

of the questions I asked. I also had them demonstrate how they used their pumps (Figure 1), took their blood sugar levels, and how they analyzed carbohydrates contained in foods they ate.

After discussion and interviews we evaluated the important points of the interviews and chose topics to highlight through photographs. Some things we all agreed on were harder to describe through photographs than others, but we attempted many different topics. Then we all sat down and chose which pictures best suited the ideas we wanted to get across in the photo-essay. We worked collaboratively to determine what topics were most important to the group while also keeping in mind what was best for the ethnography as a whole.

Routine

One of the first things we talked about was management and routine of diabetes by the students. They told me that there are many times when they should check their blood sugar level; some of those being when they first wake up, before they eat, and when exercising. (Figure 2)



Figure 2: After counting carbs and checking insulin levels Courtney will evaluate how much insulin should be given.



Figure 3: Test taking for Courtney, Maddie, and Ryan, when having either high or low blood sugar levels, is difficult.

Although Ryan admits that he does get lazy throughout the day and forgets to test. After meeting with the group a couple of times I noticed them mentioning they had forgotten to check earlier that day and took out their testing kits. All of them do agree that working out makes them feel better and helps them maintain their blood sugar levels. Courtney points out that when she is checking her levels she is always trying to assess and correct them to keep them at a balance. Being conscious of carbohydrate intake is a big part of analyzing, especially when eating and then working out, because they want to make sure they maintain their insulin levels throughout the meal, but also want to make sure that their levels stay balanced after a meal when they are planning to work out. One thing all of them agree on is that it is really important to not miss a meal because it puts them at an even higher risk of being too low and not being able to stay awake and concentrate in classes and meetings, which is a major part of their college schedule.

Maddie tells me that when she's stressed out during a test and her level is high it becomes really difficult to concentrate on the test, but it is even worse when she's low during a test because she is so tired and cannot focus on the exam. All of them bring some kind of sugar to tests in order to ensure they do not hit that low

point. (Figure 3) Courtney remembers one time when she was in biology lab and she had not brought her supplies in to the lab with her. She did poorly on this test because she was not able to get the sugars she needed. She was upset because her professor did not take that in to account when grading her test. Due to the fact that it was a timed lab practical, and would have the same material on the exam, her professor would not let her retake the exam. These are things the students have to be conscientious of that normal students do not really think about before going to an exam. Maddie also states when she is low during a lecture it is hard to memorize the material when, normally, she has no problem taking in the information.

Troubles

The title of this photo-essay is “Getting High” and it relates to an experience Maddie had where she was accused of doing heroin because of her use of the term to describe her sugar levels. The social norm context of this statement is generally believed to be about drugs and being high off of drugs. Because of this, she feels she has to be more aware of what she says in public even though it is lingo used as a diabetic. Another term that is highly used is “bolus” or “basal” which is in regard to giving them insulin. The pump/ monitor that all three wear (generally on the hip or off of

a belt) is what checks their basal levels and allows them to automatically calculate how much insulin to distribute at the time.

When asked how they would describe how they felt about their diabetes both Ryan and Courtney said they felt guilty about it. Ryan said that “the most damage is done within the first 5-10 years of having the disease” and although he wants to make sure he maintains his health he doesn’t want to give up some of the things that doctors recommend he gives up. Courtney feels that she is not taking care of herself, but at 19 she “wants to feel that she shouldn’t have to

give up things like a milkshake from Steak-n-Shake.” (Figure 4) It’s all about what they’re willing to sacrifice. Maddie says that she is not happy about having diabetes but she has accepted it as a new way of life. Ryan says that a lot of the guilt comes on when going to the doctor because they show him charts on how his levels have mapped out since his last visit and “show him how much he sucks.” As the students described it to me, it is similar to going to the dentist and not brushing your teeth regularly and feeling guilty about it.

Yet 100 times worse because it means they might not be taking care of themselves from a life-threatening disease.



Figure 4: Courtney: A sugary drink may make others happy but it makes these students feel guilty.

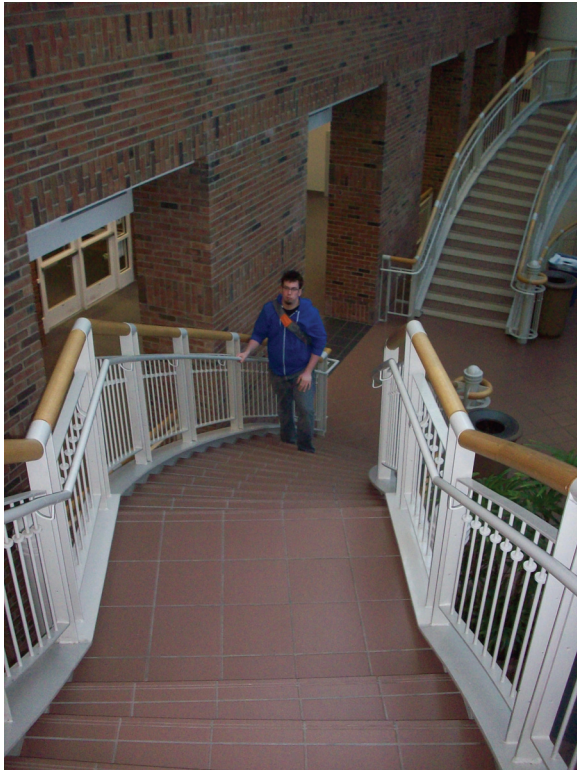


Figure 5: “It’s not like you tripped and you get back up – It’s like you trip down the stairs and you have to walk all the way back up.” – Ryan Quinn

Courtney says that when she goes home her mom still pushes her to make sure she counted her carbohydrates to balance her insulin levels and it is really hard to handle. This especially difficult because Courtney is accustomed to being at school, and away from people watching over her and her management of her illness.

Diagnosis

Ryan describes having diabetes to me: “It’s not like you tripped and you get back up – It’s like you trip down the stairs and you have to walk all the way back up.” There is never a quick fix to maintaining levels. It is a constant battle to try to balance out the levels. Ryan understands what it is like to have a life-threatening disease

because he had a congenital heart defect before he was diagnosed with diabetes and had many heart surgeries. What made him upset is that he went from one life-threatening disease to another. Ryan was diagnosed when he was 13 with diabetes and he remembers the weekend before he was diagnosed when he was vacationing in Wisconsin. He had been drinking tons of pop, even more than usual and had two of the large size *Pixy Stix*. His friends who had gone with him found that odd. He went to the bathroom 27 times in 11 hours and documented this. He went in and showed the doctor the documentation after his vacation weekend; he was diagnosed and sent to the hospital. He spent four days in the hospital, three of which he felt they were doing nothing for monitoring his blood sugar levels. All three participants described to me how they felt before they were diagnosed; it was like there was no possible way they could have enough to drink. (Figure 6)



Figure 6: The Diabetic thirst could not be quenched when Ryan was diagnosed.

It was if they were in the heat of the desert with no water in sight, except they did have something to drink, but it never was enough.

Courtney was in 8th grade when she was diagnosed with diabetes. She knew that something was wrong because she was drinking a lot and going to the bathroom all the time – around every half hour. She lost about 20 pounds at that time, and right before being diagnosed she went on a 22 hour trip to Florida. She constantly had to stop to go to the bathroom and her parents actually thought she had an eating disorder. After that trip her mom picked her up from school one day to get her tested because she is a nurse and had a feeling that it was

diabetes that was causing her symptoms. After being there for five minutes they diagnosed her, and she was put in the hospital. After she was out of the hospital she did not want to go back to school because she couldn't give herself insulin shots. Her mom had to come in at lunch time to give her the shots every day. Courtney believes she is not good with change, so it was a hard transition.

However, in high school it was easier for because in middle school she had a hard time admitting she had trouble giving herself

the shots for the first few weeks after she was diagnosed. By high school the routine started setting in and she knew how to give herself shots.

Maddie, on the other hand, was diagnosed more recently and remembers the exact date (October 23rd) when she was diagnosed. It was her senior year of high school in the middle of applications to colleges. Her senior year was going well, and she felt like it was all of a sudden that her mother wanted her to get tested. She spent four days in the hospital, and she had only expected to be in the doctor's office for five minutes. Her mom had wanted her tested because her grandfather had been diabetic, and the signs of drinking a lot and having to go to the bathroom often were familiar to her mother. All three of them caught the onset of diabetes before decay, an extremely bad point of when the disease hits the body which causes the person affected to be constantly throwing up.

Peers

When the participants were asked how they feel students who do not live with diabetes perceive living with the disease, each of them had different things to touch on. Courtney feels that other students don't think it's a big deal, especially because they believe the pump does it all for them, which it definitely

does not. Ryan and Maddie hit on similar areas that students think it is only about testing blood sugar and about the food they eat. They don't see what a rollercoaster it is



Figure 7: Hi-C Orange Lava Burst is a staple in Ryan's backpack when going to Shirk to workout.

and how a person feels inside about living with diabetes. One of the main things Ryan is concerned about is the fact that he is constantly thinking about life expectancy. The choices he makes and the risks he takes can take off time from his life and he's always thinking about how "I'm taking five minutes off of my time with my kids." A lot of things that people not living with Diabetes might not realize is the effort put in to getting dressed. (Figure 8) They always have to be conscious of the pump and not pulling the cord. It is especially difficult when putting on dress clothes such as suits and dresses. Maddie makes a point to say that even shopping is something to think about because it is exercise, and she does not want to be low when going shopping or she won't have energy to shop.



Figure 8: Tubing from the monitor always gets in the way of clothing.

When asked to describe the difference between living at home and living at college with diabetes the participants had differing answers. Ryan says at school he is not as good about checking before he eats. He also admits to having reactive parents who often get concerned about his diabetes control when it is bad. On the other hand Courtney believes she has proactive parents because they worry about her diabetes control before it gets bad. Courtney did not

notice how much her mother worried about it in high school but now that she's been away she notices it a lot more. Maddie on the other hand does not see as much of a difference because she was 17 when she was first diagnosed, much older than the other two. She believes she had been more self-sufficient at the time she was diagnosed so her parents did not need to monitor her as much as Ryan and Courtney's parents did.

Analysis

The literature I read on the subject of Type 1 Diabetes in university students has some similarities to the data I collected in my research as an ethnographer. Although some of the information I collected does not match up to Balfe's findings. On the one hand, it does seem that the students I interviewed are concerned somewhat about how they appear to other students but they also feel that other students do not see them as much different. They feel that their peers don't see that they are living with a difficult, life-threatening disease.

Another thing that Balfe's articles talked about was the fact that as students got older they became more concerned with their self-care routines. It does seem that as the Illinois Wesleyan students are older they become aware of the risks they take when dealing with their diabetes, especially because they seem to feel guilty about some of the decisions they make. One of the things that Balfe's participants highlight is the idea of life expectancy, and that seemed to be a big thought for Ryan-- that his life may be cut much shorter than the average student because he was diagnosed with diabetes at such a young age. Balfe also highlights one of his participant's remarks about not letting the disease restrict them, and that seems to be similar to Courtney's reaction with having a milkshake from

Steak-n-Shake and indulging in some sugary drinks every once in awhile.

The students who were interviewed for this ethnographic study are typical members of the group on this campus. These students are separate from the typical American students because they have to be more conscious about what foods they take in, especially the amount of sugars they eat. They also have to be aware of the amount of exercise they get and the activities they participate in. The characteristics of this community are not necessarily passed on to new members of the group because each experience is different when a child or young adult is diagnosed with type 1 Diabetes.

Conclusion

My research goals in this project were to identify the differences that the group, college students living with Type 1 Diabetes, have within the larger campus community. Some of the biases I as the ethnographer brought to this research were from experiences I had in high school with peers who also lived with Type 1 Diabetes. I had not really experienced anything with students in college living with diabetes. The notions I had about difficulties living with diabetes in college did prove true, but in different ways than I would have expected in high school. I had always thought that students constantly needed to check their

blood sugar levels, but I did not realize how much of a hassle that became, especially for students in college who have so many other things to make sure they complete. It showed me how difficult a balance between school life and maintaining diabetes is. The major themes that we've come to recognize in this process are the diagnoses of the students, the daily routine of dealing with Diabetes, and explaining to peers and others how they feel about their Diabetes. In Balfe's studies we see that as United Kingdom students become upperclassmen students and have less structure their routine falls apart when dealing with their Diabetes. In my study of these Illinois Wesleyan students, the difficulty of structure and routine does not seem to have been a problem with these students even though the structure of life as a first year student has passed. Some of the highlights from Balfe's works are on the differences between ages of the students and how they feel about their diabetes. It does not seem like there is a huge difference in my research between the different ages in the students on Illinois Wesleyan's campus living with diabetes.

One thing that I would hope researchers would really focus on is if there are any opportunities on campus that help these students with Diabetes lives easier. This might help their transition in to college and make them feel like the IWU community really cared for them and their issues.

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