

Using P-CHAT to Understand the Lives of Those with Type 1 Diabetes

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Being a type 1 diabetic often means being misunderstood because people are unaware of the difference between type 1 and type 2 diabetes. In addition, people's lack of awareness about what it's like to live with type 1 diabetes can cause extra work and frustration for people with the disease. In this article, Nenagh Gedge uses P-CHAT terms like reception and socialization to explore how people interact with diabetics in ways that can make life more difficult, as well as how diabetics can construct their representations in ways that change how they are perceived.

What Do You Think About When You Hear the Word *Diabetes*?

I'm a type 1 diabetic. Most people I meet have heard of diabetes, but they usually aren't aware that there are different types of diabetes. If they know anything at all about the disease, they may only know about type 2 diabetes. For most folks, diabetes is something that anyone can get, especially if they aren't careful about their diet and lifestyle. But that misconception can be really hard for people with type 1 diabetes. In fact, the ways that people understand and react to diabetes (as a term, or how they understand how it impacts people who have it) can really make life difficult for those with diabetes. In this article, I will use pedagogical cultural-historical activity theory, or P-CHAT, to look at the ways that people treat diabetes as a genre of illness and how their misunderstandings can negatively impact the lives of people with this disease, making it harder for us to function and to feel comfortable or accepted in the world.

To start with, I want to remind readers that **P-CHAT** is a framework the ISU Writing Program uses that can help people to understand and

Literate Activity

“Developed by Paul Prior (1998, p. 138), the term ‘literate activity’ is meant to address all of the many ways that texts are part of people’s lived experiences in the world. It extends beyond our typical ideas about ‘reading’ and ‘writing’ to include the broad range of practices and processes we employ in the creation and use of a wide array of texts” (Roozen 96).

analyze different kinds of literate activities that humans engage in. In this article, I guess you could say that I’m looking at *people with diabetes* as a **genre**—or as a kind of text that people read—and how these readings impact the way diabetics are seen in the world. People often attribute certain characteristics to their understanding of what a diabetic is, and I want to talk about these understandings as a kind of **literate activity** in which the P-CHAT concepts of reception and socialization both play a part.

According to the ISU Writing Program’s website, **reception** “deals with how a text is taken up and used by others. Reception is not just who will read a text, but takes into account the ways people might use or repurpose a text (sometimes in ways the author may not have anticipated or intended).” So in the case of diabetics, reception specifically deals with how people with diabetes are seen and understood by others, how this understanding impacts our interactions, and even how we live with and manage our disease.

Welcome to My Life

I have been singled out as different ever since I was diagnosed with diabetes. I was seven when I was diagnosed. This was back in 2008. Common symptoms of diabetes are an increased need to use the bathroom and increased hunger and thirst. These symptoms are seen in both types of diabetes, but type 1 is usually diagnosed in younger people whereas type 2 is more often diagnosed in older individuals (although younger people can also get type 2). Type 1 and 2 diabetes are alike and different. Type 1 diabetes is when your pancreas completely stops working to produce insulin. Type 2 diabetes also involves the inability to produce insulin, but in addition, cells in your body aren’t able to use insulin, so you end up with high levels of sugar in your blood (“Type 2 Diabetes”). The biggest misconception is that people think that only overweight people get type 2 diabetes. Though this is one reason why people may have type 2, not everyone with it is overweight. The pancreas is a pretty important organ in our bodies. It is used for digesting food and managing the use of sugar for energy after digestion. It enables sugar to enter your cells so that it can be used to create energy (“How Does the Pancreas Work?”). If we do not have insulin for a certain amount of time, we will go into diabetic ketoacidosis which can lead to death if not treated.

Before I was diagnosed, my Mom noticed that I wanted more snacks and that I was very thirsty all the time. Because she noticed all these changes, she decided to take me to urgent care. From there I underwent a range of different kinds of testing to get my diagnosis.

Now, multiple times a day, I must prick my finger, draw blood, and get my blood glucose. I also have to do this every time I eat or drink something with carbohydrates. If I do consume carbohydrates, I have to administer insulin into my body. Thankfully for me, I have an electronic pump that provides the insulin. But for those who are not lucky enough to have that advanced technology or even prefer to not have it, they must personally inject themselves with a needle. This, of course, draws attention when in public because many people do not understand what we are doing and why we are doing it. When you are young, people occasionally will talk to the parent instead of directly to the child. My Mother experienced this when we were out in public while I was growing up. My Mother was there the most for me growing up when it concerned my diabetes, and she was always there to educate anyone who asked. A couple of years ago my family went to go see Niagara Falls in New York. It was a very beautiful, sunny day. This was great except that the sun can be a bit much. In short, the sun and the amount of walking we did made my blood glucose go down. I needed sugar fast, so my grandmother skipped a line at a stand to get me something to drink. We got so many disgusted looks because my grandmother skipped the line. She tried explaining why I really needed something immediately. The workers were hesitant to give me anything and mentioned getting in line. A very kind stranger who happened to be a doctor came over and insisted that we were telling the truth and that this was an urgent matter. I think this is a great example of how we as diabetics struggle out in public. These people didn't know why it was so important that we got to skip the line.

In addition to being curious about the activities diabetics might need to engage in, a lot of people confuse the two types of diabetes, often only mentioning type 2. When a person who doesn't know about the types of diabetes or how they differ is talking to me about my disease, their ignorance can sometimes cause them to make inconsiderate comments. Their reception of the genre of people with diabetes is not researched, so they make mistakes, but it's more than that. In a paper I wrote a year ago, I said, "I get all these ignorant questions that can be offensive too." Questions I've been asked have included things like, "You have diabetes? But you are so small," or "Oh, is that the good one?" People have also asked, "Can you eat that?" and "Do you have it because you had too much sugar?" or "You don't look like you have it," as well as "Did you do something wrong?" If you did not even wince at one of those, then you should go read them again. And these are questions

The Problem with Reception

In the ISU Writing Program’s concept of P-CHAT, the concept of **reception** is used to discuss how people take up and use texts that are produced by others (ISU Writing Program).

But reception in this case involves the way that humans understand and identify people with diabetes. It’s been my experience that my own representations (of myself and of my disease) don’t always match up with those of other people, and their reception of me (and my disease) can sometimes have negative consequences for me.

that I have heard frequently throughout my life. Like I said before, as I’ve gotten older and people are interacting more directly with me instead of with my parents, I now experience some of the insulting things that come out of their questions.

These people are *taking up* my identity as a person with diabetes, but because of their lack of knowledge and their insensitivity, their recognition of me is a *negative* recognition. I think it’s important to talk about this because too often we see reception as a more neutral (or even positive) kind of activity. When this term is used in P-CHAT, it’s often just described as the straightforward ways that people go about visualizing, understanding, and interacting with texts. In fact, the focus is often on the

freedom and innovation that can occur when people take up a genre or tool and work with it, changing it or using it differently. But, in some cases, if people lack knowledge and experience or are insensitive, these uptakes could potentially be damaging to others.

Learning to Cope with Socialization as a Diabetic

In P-CHAT, the concept of **socialization** deals with “the interactions of people and institutions as they produce, distribute, and use texts. When people engage with texts, they are also (consciously and unconsciously) engaged in the practice of representing and transforming different kinds of social and cultural practices” (ISU Writing Program). So for me, because I wasn’t really encouraged or guided to talk about my disease—because I wasn’t *socialized* as a person with type 1 diabetes in positive ways—I ended up feeling like the activities I had to engage in to control my diabetes were something I had to hide. I feel like this could be a reason I might not be the best at managing my health. When you feel like you have to hide what is considered different, you tend to forget that you have it. I tried to hide my diabetic supplies when going to test my blood sugar while I was in middle school. The things I try to hide nowadays also include the modern technology that I wear. One of the devices is a pump that carries insulin. I can put this wherever, but I tend to put it on my stomach the most so that it is out of sight and under clothes. The other device is used to check my blood glucose numbers without having to

prick my fingers all day. This, as of right now, can only go on my arm. These things are out of the ordinary for most people because a lot of people are not socialized to them and don't see many others with them. When diabetics feel like we need to hide these tools for dealing with our disease, we may not take care of ourselves as we really should. I see the impact of this when I go to the doctor to see how I'm doing. When I go and my numbers are not where they should be, the doctor will tell me the reality of the situation. As someone who was diagnosed young, this has taken a toll on how I take care of myself. I will be honest in the fact that I do not take care of myself the way I should. When you are not responsible for yourself, your body will slowly start to shut down or you will start to see problems. For those with diabetes, this includes worsening of eyesight, problems with your limbs, and more. This is an example of how people's reception of diabetes impacts the socialization of how diabetics are perceived, which then influences the representations that diabetics may have of themselves.

But the socialization of a person with diabetes, even when it happens openly, is not always a good thing. As I have gotten older and people have become much more willing to talk to a teenager, harsher comments have come into play. The socialization of people with diabetes in terms of media, like advertising for products, isn't necessarily problematic. These images (print advertisements or commercials) are mostly just there to advertise products (like medications, testing supplies, etc.). So, our representation in these genres is just as another human with a little bit of a different life. I have never had any problems with representations of diabetes in this area. We (diabetics) thankfully have not been frowned upon in that particular world of writing. The area I am really aiming to talk about in this article is the more personal kinds of socialization—the ways that everyday people we interact with might talk to us or about us, including both labeling us as “different” and misunderstanding our condition and how we live with it. So as diabetics are socialized in these ways, the impact can be both harsh and hurtful. This can then impact the representations that diabetics have—about themselves, about strategies for managing or talking about their disease, or just about how they interact with people who do not have, or even know about, diabetes. When diabetics grow up hearing negative things about diabetes, it sticks with them. This can change how they act in public and how they treat their diabetes. Most people I am friends with who have diabetes tend not to take care of it as much as they should because of the embarrassment they feel about it. Some people think it's easier to avoid using tools like monitors or glucose pumps in order to avoid the awkward stares or comments we get when we take out our medical supplies.

The Impacts of the Negative Socialization of Diabetics

Examples of this kind of negative socialization can be found in the article, “Type 1 Diabetes in Young People: The Impact of Social Environments on Self-Management Issues from Young People’s and Parents’ Perspectives,” by Beth Milton, Helen Cooper, and Joy Spencer. These authors studied teens in the UK with type 1 diabetes and found that there were a range of “barriers to self-management in school and social environments” (Milton et al. 48). Some teens reported problems at school, such as difficulty with teachers who did not want to allow them to leave the classroom to get food to treat episodes of hypoglycemia or who restricted where they could do injections (Milton et al. 53). Others discussed being called on to discuss their disease in class or struggles with motivation related to their glucose levels. Several of the teens and parents in the study discussed the struggle of not wanting to disclose their diabetes to friends, or where aspects of self-management caused them to feel unwanted attention (Milton et al. 54). In another study, published in 2006 by Judith W. Herrman, some children reported that dietary restrictions and “being treated differently” were two of the highest costs of living with the disease, as children claimed, “Everyone stares at me, I feel different.” One child stated, “I don’t like all the attention,” and another related that, “we’re not contagious . . . we can do the things other kids do” (Herrman 214). Both studies also found that positive support and acceptance (from family and friends and classmates) had a positive impact on teens’ ability and willingness to adhere to “self-management regimens,” while the perception of a negative response had the opposite impact: “Lack of peer support or young people’s perceptions of negative peer reactions may partly explain reports of reduced adherence to the diabetes regimen during adolescence” (Milton et al. 56).

This research study illustrates my point about how type 1 diabetics can be impacted by the socialization of their disease. People with diabetes should not feel as if they are an alien because of their disease, and more importantly, a positive socialization can help people be more committed to managing their disease, which can improve their long-term health outcomes.

Another aspect of negative socialization for people with type 1 diabetes is that the prevalence of type 2 diabetes can cause misunderstandings and can even tend to make people with type 1 diabetes invisible—and this happens everywhere. For example, as I did research for this article, both looking at research articles and at people’s comments and thoughts in various online spaces, I came across many, many examples related to type 2 diabetes. Often, when clicking on a link related to diabetes, I’d find that type 1 was mentioned somewhere in the article, but it was not as equally represented as information

about type 2. In some ways, it seems as if type 1 diabetics don't exist in the social world. That is, in terms of information and representations, the socialization of diabetes and diabetics seems to be focused predominantly on type 2. I've learned that if I want information about type 1 diabetes, I must type it out in my search in that very specific way. The reason for this gap in information about the different types is most likely based on how common each of them is. When looking at the American Diabetes Association's website in the statistics section, I was able to get the numbers. "In 2019, 37.3 million Americans, or 11.3 percent of the population, had diabetes. Nearly 1.9 million Americans have type 1 diabetes, including about 244,000 children and adolescents" ("Statistics about Diabetes"). So only 1.9 million have type 1, which means that 35.4 million have type 2 diabetes. This huge gap in numbers is why it can be hard to find representations of type 1 diabetics and the issues that they face when searching online. This aspect (or lack) of socialization for type 1 diabetics made me sad to think about. The Internet is so big and full of information, but it seems, in some ways, to make me and people like me invisible.

Rethinking Diabetic Socializations

One of the things diabetics can do is speak and write more openly about not only their experience with the disease but also the activities they engage in to manage the disease on a daily basis. Often diabetics write about our stories because of the sad accusations and comments we get from people. We try to recognize the faults in society by writing. When we do this, we try to represent ourselves and our community in ways that are more accurate and complete and not misleading. Others (people without diabetes) need to know how to talk to and think about those with diabetes, rather than just saying something ignorant or unsupported without thought or consideration. These kinds of new representations can be used to impact the overall socialization of diabetics, just as similar kinds of work with other disabilities can change those socializations. Socialization is a key part of the change people with diabetes can impart by creating new representations through different kinds of literate activities.

Representing Diabetes as a Diabetic

Next, I'd like to talk a little about what diabetics can do to create new representations of diabetes and of themselves as diabetics. First, what we can do as a community of diabetics is speak out and educate. As I have gotten

older, I have gotten sick of all the inaccurate information that people take as true about type 1 or 2 diabetes. I have listened to what people have said and then corrected them. I do not hate or judge people who don't have an accurate understanding of what diabetes is, but I am getting to the point where I want to be more active in helping to change these false conceptions. Another thing we diabetics should be doing is educating those who are close to us. Getting accurate information out into the world, even on a small scale, will help to give us one less person who will judge us.

One thing that is super important to our community is coming together for the Juvenile Diabetes Research Foundation (JDRF), or any other kind of organization that supports diabetes. For example, I have done the JDRF One Walk multiple times and each time have put together a group of friends and family to walk with me and raise money for JDRF research. This is a great way to get out and meet people with the same disease. It is also a way to further educate people by spreading the word via the Internet. When diabetics come together as one big community, it shows that we are fighting both the disease and people's wrong perceptions of it, together.

Final Thoughts

I didn't realize how big and personal this topic would be until I really began thinking, researching, and writing about it. My diabetes has been with me most of my life, and the social aspect has never changed the way I feel it should. That is, in some ways it feels like nothing has changed when it comes to how people act around diabetics and their understanding of the disease and the work that goes into living with it. If anything, I have learned how underrepresented we are as a community within the larger socialization of diabetics in our culture.

This has made me realize how important it is for me to write about the way the disease affects my life and how I would like people's views to change. In the past I have written papers about diabetes and even had a website at one point (though it is not live anymore). I think that since social media is a part of our lives now, more people should share their life experiences with their audiences. I have posted multiple times about where there are differences between my life and others' lives. There are days that I would love to write a book about my life and what it takes to live the life of a type 1 diabetic, but that might have to wait for a while.

If you want to learn about diabetes, look it up. Make sure you are reading from sources that are credible though. You can also go to social media and

find influencers that have diabetes. Then you can get a real look at what our daily lives can look like. There is also another article in the *Grassroots Writing Research Journal* that you can read that is about diabetes. It is called “Beyond Type One” by Lisa Hanimov (issue 12.1, Fall 2021). If you read it, she tells her story from the beginning and how she lives with diabetes. Her article is a great look into how we live and think about our lives. For now, though, just remember that we are all human. Diabetics just need extra gadgets to keep us going.

If I can try to be a voice that type 1 diabetics and many other communities may need, then I will try my best to do so. I will make it a part of my journey to teach those who are not as educated about each type of diabetes. I would like to help in the task of changing how type 1 diabetics are socialized and understood in our culture because positive support can help people with diabetes live better and healthier lives.

To the Reader

Whether you or a loved one have experience with either form of diabetes or not, I hope you can take the information I shared with you into consideration. You do not need to make it your job to go out and teach people the things I have mentioned, but I do hope that if you hear someone share misleading information that you will politely correct them.

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Nenagh Gedge is a junior majoring in psychology at ISU. She has had diabetes since she was seven years old and is still fighting for a cure. She loves reading and doing fun projects like knitting. Telling a story like this is very important not only for her but also for those who do not have a voice.



Notes