Through the analysis of the implications of the medical and social definitions for type 1 diabetes, I address the rupture these create in the embodiment of a disability identity for people with type 1 diabetes. First, I will provide the medical background for diabetes and demonstrate the over-medicalization of blood glucose data. This information and analysis will culminate in demonstrating the limitations of the medical model. Second, I will focus on the social model and its exclusion of fluctuating situations of diabetes, which creates a fragile liminal space between the binary of ability and disability. Next, I will offer a theorization utilizing facets from both models to better represent the diabetes identity. Finally, I will employ a disability studies framework to demonstrate how this hypothesis is embodied in personal testimony on diabetes blogs. My focus will utilize a sample of posts from Six Until Me penned by Kerri Sparling, who has written within the diabetes online community for approximately ten years. She shares the daily details of a life with diabetes as a personal release to establish community and connect with others. Specifically, I will emphasize her reflections on the lack of consistent identity, social perceptions, and emotional impact of diabetes.

**Medical Aspects of Diabetes**

First, the medical definition of type 1 diabetes is outlined by the pancreas’ failure to produce insulin, a hormone required for con-
version of the glucose in food to energy. Insulin is necessary for the function of all organs; therefore in type 1 diabetics without insulin, the body cannot thrive. In patients with type 1 diabetes, synthetic insulin is infused to compensate for the body’s deficit. But, it is not a simple dose; rather, the amount of insulin is calculated based on many different daily factors during the course of any day, such as type and amount of food, stress levels, exercise, amount of sleep, illness, diabetes itself, and so on. The effectiveness of the dose is then monitored multiple times a day by checking blood glucose values via finger sticks. Rudimentarily, if the glucose level is too high, more insulin is needed. If the glucose is too low, it is due to not enough glucose or too much insulin. Kim Vlasnik, author of Texting My Pancreas, another diabetes blog, provides a basic breakdown of blood glucose range in a gif (figure 1). This graph depicts the expansive range of potential glucose values including the minute “normal” range. The first grouping, approximately 0-70, is considered low—meaning not enough sugar is present in the blood stream for the body to function. Vlasnik labels it as “debilitating,” cuing symptoms of headache, shakiness, fatigue, hunger, fast heart rate, sweating, and as it approaches 30, potential seizure and death. Next in the miniscule 70-120 “normal” category, the target glucose and insulin levels are balanced. This is a representation of success, as the patient managed to effectively calculate the exact body needs, usually drawing at least a smile, if not a more jubilant form of celebration. She notes the “uncomfortable” range, from 120-400, where the increase in glucose levels demands action and more insulin. At around 180, “high” symptoms, such as

![Figure 1. Still image of gif. “This is why I’m high,” simplifying blood glucose ranges in a concise view (Vlasnik 2014).](image)
hunger, thirst, frequent urination, lethargy, and irritability begin. The kidneys are flooded with sugar, and the body slowly prepares itself for survival mode. As glucose levels increase the severity of the symptoms also increase. Finally, in the “you need to go to a hospital” range, the body shuts down due to the overwhelming lack of insulin, high glucose, and the patient and body’s failure to compensate, leaving the patient approaching a coma state. At any point outside of “normal” there is action to try to return back to that range, without overshooting, as either side of normal has the potential to become disastrous. In relation to a disability identity, once the glucose level leaves the “normal” range, the difficulty of passing as non-disabled also increases. I would like to emphasize that all of these decisions for care fall to the person with diabetes at all hours of everyday. Essentially, the individual with diabetes acts as their own organ, a full time job, always requiring at least a little bit of thought during all aspects of life. The management can be described as both calculated and a fast-and-loose guessing process, where the patient can attempt to account for the many different factors, but also must make an educated guess on what their body requires.

Models of Disability

The medical model of disability describes the current perception of diabetes by society, despite being rejected by the disability community. Tom Shakespeare (2013) highlights the medical model’s outline of disability as “reduc[ing] the complex problems of disabled people to issues of medical prevention, cure, or rehabilitation” (p. 216). The medical model implies that disability is the only dimension of a person and psychologically ties a person with diabetes to the intricate management of their condition. Each glucose value intimately reflects the individual’s previous choices and actions. The patient is expected to account for unaccountable bodily changes, otherwise it is seen that he or she has failed, because there is a link between their decision and the data outcome. Furthermore, medicalization drives
people with diabetes to feel blame and shame because the person is expected to appear non-disabled, which is not always possible. Clearly, there are issues with the attachment of the person to the disability, which is why historically, the medical model has been rejected by the disability community.

Instead, we turned to the social model as a better representation of people. It is centralized around a statement by the Union of Physically Impaired Against Segregation quoted by Tom Shakespeare (2013) which states, “[d]isability is something imposed on top of our impairments, by the way that we are unnecessarily isolated and excluded from full participation in society” (p. 215). This suggests that disability is more than the inconvenience of the condition; instead disability compounds the underlying challenges. To create this theory, the social model requires that, “disabled people [be] distinguished from non-disabled” (Shakespeare, 2013, p. 216). Instantaneously, this creates a binary: a person must fit one category or the other, which diabetes challenges. Diabetes and other fluctuating disabilities are critiqued as not fully classifiable as disabilities, because the situations requiring accommodations and therefore exclusion from “full participation” are not always present. Specifically, for people with diabetes, there are many times when the condition is invisible and the person is able to pass as non-disabled. Despite lack of visibility, the pancreas is still non-functional, so the patient compensates, and therefore is unable to be deemed “normative.” The inconsistency of disability status creates the appearance that type 1 diabetes is not a disability, but simply something extra that the person is expected to overcome and pretend to homogenize with “normal.” Those with diabetes are stranded in the liminal space between the rigid categories of “ability” and “disability” because they don’t fully embody either definition, but there is a lack of in-between or capability to move within the labels. This creates a fragile balance: the person is close to both categories, but lacks a discrete identity. It leaves people questioning where do I fit?
Diabetes’ Disability Identity

To address the idea of diabetes identity, we must consider the complex development of the liminal space, and the need for fluidity between categories, to better account for all aspects of the condition. People with type 1 diabetes need a space for identity, not simply acknowledging they interrupt the mutually exclusive classes and could fit in between like the middle of a Venn diagram. Rather, we need to create an effective representation within the social model that accounts for the fluidity and fluctuation of disability status. For this modification to be successful, it requires a mixing of both the medical and the social model. The medicalized blood glucose values can be used to justify the location of a person with diabetes in the social model, as that number not only dictates the medical treatment needed, but also the required modification of a life activity or social implications. Instead of placing the disability on the patient, I posit the medical model could dictate how people with diabetes are situated and transition within the binary of the social model. For example, the graph by Vlasnik can be utilized, as the general categories dictate different needs and social accommodations. Plotting these categories visually is seen in figure 2. The

![Image of Venn diagram with ‘Ability’ and ‘Disability’ labels](image.png)

**Figure 2.** A visual representation of a single path over time demonstrates traveling through the liminal space and the social model.
“normal” space, represents virtually no action needed, therefore the person is not only able to pass as non-disabled, but may also choose to not consider diabetes a disability. People with diabetes never fully exemplify “able-bodied,” because there is always a non-functioning pancreas in their bodies, like a limit in calculus approaches zero, but never actually equals zero. This essentially represents the liminal space between ability and disability. Next, in the “uncomfortable” range, the blood glucose value dictates a need for insulin and perhaps residing in the outer edge of disability. While the blood glucose rises, one continues to associate more and more with the disability identity as the modifications of activities also increase. Then, in the section of “you need to go to a hospital” or “debilitating” there is the need for significant modification of activities, for accommodations, and possibly for medical attention. Here, one would acknowledge these needs via identifying as disabled, amidst the center-most portion of the circle. In essence, this demonstrates how the glucose values dictate the transition through the disability, some-what-in-disability, passing for “normal,” and everything in-between. Instead of the precarious balance between almost ability and sort-of disability, this theorization better represents the fluidity of the disability status of diabetes and offers an understanding of the identity. It accounts for the times when things are not fine and when diabetes demands attention, even if that is not always constant. To illustrate these ideas, I consulted personal blogs of patients with type 1 diabetes.

**Emotional Evidence**

Kerri Sparling’s candid mantra “diabetes doesn’t define me, but it helps explain me,” appears below the title on each page as an almost constant rebellion against the medical model. This mantra acknowledges the role of type 1 diabetes without the individual being equated to the condition (Sparling, 2015). Furthermore, the blog recognizes the changing disability identity when she openly states, “diabetes makes me walk the precarious fine line between ‘I’m sick’ and ‘I’m not’ and
the whole in-between that makes diabetes invisible, and yet so seen” (Sparling, 2013). She discusses when diabetes is mostly an inconvenience or causing the low where we must ask for help and be reassured that we are, indeed, okay (Sparling, 2012; 2007). This reflects the movement within the categories of the social model, as moments within a day can cause drastic differences in the need for accommodations.

Second, a major theme is the discussion of social identity and the problematic categorization of people with diabetes as not disabled. Sparling (2014b) ruminates, “the public perception ... is that it runs Tamagotchi-style, a simple matter of pushing the right buttons and following the formula.” There is a lack of understanding from those who are “abled” or “disabled” because neither believe diabetes fits and have therefore failed to comprehend the weight of diabetes. This parallels the societal lack of understanding because it does not fit in either group, and therefore is seen as “not real” and the experiences are discredited. Finally, there is the psychological impact of the medicalization of diabetes. Sparling (2014a) speaks to removing the emotional attachment when she says:

> I need to find ways to stop myself from assigning emotional worth to my blood sugars. Instead, I need to see them as what they are—information. ... growing up blood sugars were either ‘good’ or ‘bad.’ ... each ‘good’ comes with a guilt-inducing ‘bad’ counterpart. ... It’s a psychological war zone, attaching these type of emotions to blood sugar management. Walking the tightrope in pursuit of in-range numbers is difficult enough, with all of the variables, but positioning the rope over a nest of emotions-in-the-shape-of-alligators makes it that much harder (p. 101).

Without theorizing the liminal space of the social model, diabetes reverts back to the medical model, dictating the over-medicalization of the blood glucose values tying them to self worth. This is because of the social model has failed to include those with fluctuating dis-
abilities and therefore people with diabetes linked to all aspects of their condition. The blog effectively demonstrates the rupture within the disability identity theorization, due to the clear lack of support, representation, and understanding of diabetes identity. This blog is only one example of many patient responses, and it demonstrates the shortcoming in the theorization of disability identity.

Application to Disability Studies

In the social model, disability studies has failed to fully recognize the complex embodiment of disability by people with type 1 diabetes. Due to exclusion from the formulation, hidden disabilities “are assumed to be less real or less difficult than the struggles of people with more apparent disabilities,” perhaps because the disability studies community rejects the validity of their ever-changing status (Valeras, 2010). The bifurcated social model leaves people with diabetes without representation. Not only are people with diabetes expected to function as their own pancreas, but also to do it flawlessly in order to pass for “normal” without recognition of the challenges they face. Second, the exclusion from the social model withholds Shakespeare’s (2013) claim, “the social model has been effective psychologically in improving the self-esteem of disabled people” (emphasis in original, p. 217). People with diabetes, who face a psychological weight from a lack of true identity, should be included in an effort to relieve this burden. The social model’s attempt to acknowledge society’s discrimination and stigma of disability becomes more challenging for people with diabetes because the condition does not always embody the typical criteria. The way individuals with type 1 diabetes pass for able bodied, but still carry the disability as we homogenize with the norm should be recognized. Modification of this theorization of diabetes’ disability identity allows us to have a true depiction of the weight our disability bears. Without these adaptations, the social model’s bifurcations fail to acknowledge people with type 1 diabetes, leaving us disembodied in the liminal space, without representation, and revert back to
the oppressive medical model, where our management decisions are directly tied to our self-worth.

References


AUTHOR BIO

Victoria (Tory) Sylvestre is an undergraduate nursing student at the University of Connecticut, with a strong interest in disability studies. Her research interests include chronic illness, coping mechanisms, and invisible disabilities. Specifically, as part of the University Scholars program, she is pursuing research surrounding type 1 diabetes, adolescent development, and the role of healthcare providers on emotional impact, shame, and stigma created by this condition. Her plan is to pursue a career in pediatric nursing with the intent of one day earning a doctorate degree in nursing.