

Pumping and Passing: Mediating Diabetes Treatment and Health Identity through New Media

As of 2012, approximately 30 million people in the United States, or 9.3% of the total population, live with diabetes. A chronic illness which affects the body's ability to break down and use carbohydrates and sugars via the body's insulin hormone, diabetes mellitus—the so-called “sugar disease”—is also the seventh leading cause of death in the U.S. (CDC 2015). These millions of people with diabetes must maintain their body's blood-sugar levels through a variety of treatment options based on their particular case, many of whom require direct injections of artificial insulin every time they eat (people with type 1 diabetes in particular). It is no surprise, then, that researchers have attempted to find ways for diabetic patients to receive these treatments more efficiently, and in less cumbersome and complicated ways. Since the late 1970s, researchers in biomedical technologies have funneled millions of dollars and years of work into developing portable insulin pumps, which can be filled with several days' worth of insulin and injected by the user on an as-needed basis.¹

These new technologies have made insulin injection treatments much simpler and quicker, especially in promptly dealing with moments of dangerously high blood-sugar levels, but they have also constrained the user in meaningful ways. Even though pumps have continued to get smaller and smaller, they are still bulky pieces of machinery which patients must carry around with them all day everyday. What is more, the pump must be connected to the body at all times via an “infusion set”, “inset”, or simply “site”, that inserts a subcutaneous tube into fatty tissue for gradual absorption of insulin. Doctors and researchers recommend that this site be attached within a few inches of the belly button, since the tissue there seems to diffuse the hormone into bodily systems most effectively. That means this site is always front-and-center, so to speak, which greatly limits how and where users can carry the pump itself;

¹ Research funding has increased dramatically since the U.S. Congress passed The Medical Device Regulation Act, or Medical Device Amendments of 1976, which added classifications and regulations for devices intended for medical use to the Food, Drug, and Cosmetic Act of 1938.

after all, the tubing that connects the two can only be so long. The visibility of either the pump or the infusion site can be uncomfortable, if not anxiety-inducing for many people with diabetes who do not want these objects to signify their medical/social status and mark them as capital-D “Diabetic”—for being marked with *any* material (whether bodily or technological), enacted, or discursive signifiers associated with Diabetes in the contemporary U.S. places people outside the realm of the unmarked, inclusive, able-bodied “norm”. Several different physiological processes or “types” of the disease fall under the auspice of “Diabetes”—each with varying causes, effects, and treatment needs—but they are all conflated and treated as a single, choice-driven illness in the popular imaginary that could be prevented through “good” behaviors, regardless of how flawed or inaccurate those associations may be.

TeeOneDee, self-proclaimed YouTube Diabetic “Gooroo”, and other pump users-turned-advisors have responded to these and similar issues by uploading videos discussing and demonstrating the best practices for “wearing” their insulin pumps—the most common action word used in each case—for the dual purpose of: 1) hiding the device out of sight, and 2) making its use the least awkward and in-the-way as possible. In what follows, I will analyze TeeOneDee’s instructional video “Where to put your insulin pump” as a representative case study to identify the semiotic and rhetorical situation in which it is set, as well as the narrative programs that can lead users to multiple objects of value simultaneously: on the figurative level, treating chronic illness with the least amount of interference to daily activities and *passing* as non-diabetic; on the discursive level, feeling “normal” by turning “non-normal” signifiers (i.e. technological treatment acts) into unacknowledged, empowered, perfunctory acts of passing.

The Speech Event

In early 2013, a young woman with type 1 diabetes known on YouTube by the username TeeOneDee was asked by several of her followers to create a video telling/showing viewers how and where she keeps her insulin pump. As a long-time pump user, TeeOneDee decided she may have some insight to offer on the subject and released a video titled (appropriately), “Where to put your insulin

pump”. Most often, she begins, she clips her insulin pump to the inside of her bra—it is out of the way, no one sees it, and usually she doesn’t even acknowledge it herself. Often, she points out, the tubing that connects her pump to her infusion site sticks out a bit, so she always makes sure to tuck it neatly away. Why is this the best place?, she asks rhetorically. “You can’t even see it! . . . That’s a really great thing about being a female and diabetic”, she claims. Even when she is sleeping, she clips her pump to the front of her shirt, since “girls already have a chest, if you know what I mean”. If that bothers you, of course, you can purchase longer pump tubing and just place your pump out away from you on the bed while you sleep (unless you’re a “flipper”, as she calls it). Some companies have produced Velcro straps and other accessories designed to help people wear and hide their insulin pumps, she points out, though she has never really found them all that helpful. No, she reiterates, the bra is the most convenient place to wear it—“You can’t see my pump! There’s no proof of me being diabetic!”²

In order to analyze and understand how TeeOneDee’s narrative program works, it is important to establish a few the factors of TeeOneDee’s speech event, the primary narrative functions at play in the narrative, as well as the actantial roles that correspond to those functions.

Addresser: In this speech event we have one primary Addresser. TeeOneDee, the YouTube username for the woman who produced and uploaded the video under consideration here, is type 1 diabetic herself. (hence the decision on this particular username: TeeOneDee >> T1D >> Type 1 Diabetic). The speaker in this case identifies her relationship to the message up front by placing a signifier on her YouTube account (and by connection herself) that acts as both a Name and a Symbol, as defined by Thomas Sebeok—on the one hand, a Name in that the actual lexeme constructed as “TeeOneDee” is meant to point to and represent her and her online presence specifically, not necessarily any broader group or class; on the other hand, a Symbol in that any signification of “type 1 diabetic” is purely

² “Where to put your insulin pump,” *YouTube* video, 7:36, posted by “TeeOneDee,” January 17, 2013.

conventional and relies on another Symbol, “T1D”, as well as a set of very particular Codes and Context to make that connection (Sebeok 1976: 134-140).

Addressee: Identifying an Addressee for this speech event is complicated by the fact that the Addresser’s intended audience may not necessarily coincide with the actual viewer. While the intended (or imagined) Addressee is very clearly outlined as diabetic insulin pump users, the nature of this public, digital medium makes it impossible to limit access to this communication to only first- and second-person actors. Every level of the Sender-Receiver relationship outlined by Allan Bell, including all third-person actors such as Auditors, Overhearers, and Eavesdroppers, can access this event at any time (it should be noted that my own participation in this speech event is clearly third-person, since I am not diabetic and therefore not an insulin pump user, though whether that role is filled as an Overhearer or an Eavesdropper is difficult to define considering the anonymity of online forums such as YouTube) (Bell 1997: 272). And though it often goes unspoken and unidentified, TeeOneDee is clearly envisioning a female Addressee, as will be demonstrated more fully below.

Code. Much of TeeOneDee’s language is littered with references to cultural and medical objects or phenomena that may not signify the same meaning to audiences without background knowledge in those subjects. Thus, special attention must be given to the Code, as Roman Jakobson calls it, of this particular speech event (Jakobson 1956: 73). Even the creator’s username, as I pointed out above, is an example of the necessity of the Addressee’s awareness of the code specific to diabetes and diabetics. But the codes necessary for this communication to effectively pass from one actor to another go far beyond the acronyms and wordplays, reaching into the realm of gender and health norms against which TeeOneDee frames her narrative. Gender-specific standards of beauty, for example, undergird the very need female pump users feel to hide their use of these technologies—and through the cultural convention of “wearing” them, no less. Doubled up by a set of social norms that place a “diseased” position such as “Diabetic” outside of a generally defined position of normality within what Robert McRuer calls the system of “compulsory able-bodiedness” (McRuer 2006: 2). These social realities frame TeeOneDee’s ability to advise, often without her own awareness of those constraints.

Narrative Functions and Actantial Models

The three other major factors of the speech event as outlined by Jakobson—Message, Context, and Contact—have already been outlined in the introduction of this essay, and it is thus unnecessary to explicate them further here (Jakobson 1956: 73). However, it is worth reiterating the Message once again in order to establish and analyze the primary Narrative Functions and Actantial Models, as defined by A.J. Greimas, for this instructional video: TeeOneDee offers prescriptive advice on the “best” practices for wearing an insulin pump (Greimas 1966: 197-221).

By following these instructions, the viewer-user can expect two narrative outcomes: first, the viewer-user’s experience with their medical device should be more comfortable and less of a physical/physiological burden, in turn minimizing its unwanted implications for the user’s daily life; second, the viewer-user should know how to hide their pump in a way that will not make their personal health and illness visible to those around them. Therefore, within the sphere of “Wearing an Insulin Pump”, we can be separate at least two narrative functions as follows:

f(Minimizing Insulin Pump’s Unwanted Impact on Day-to-Day Life)

and

f(Hiding the Insulin Pump)

Both of these functions will have similar actantial models, since many of the actors and processes involved will be the same or similar, but with some key differences on which the narrative meaning of each function hinges:

	<u><i>f</i>(Minimizing Insulin Pump’s Unwanted Impact on Day-to-Day Life)</u>
Sender -	Insulin pump user/daily responsibilities
Receiver -	Insulin pump user
Subject -	Insulin pump user
Object -	Wear the pump comfortably/out of the way
Opponent -	One’s own chronic illness, task-specific clothing/movement requirements, placement of inset, the pump (blocky), bust size, women’s fashion trends, beauty standards

Helper - Bra, bust size, tights/bike shorts, pump bands, remote-operated blood-testers, specialty under garments, pump clips, private spaces (such as bathrooms), pump slip (for a dress)

and

f(Hiding the Insulin Pump)

Sender - Insulin pump user/fear or anxiety based on social norm
 Receiver - Insulin pump user/other social interactors
 Subject - Insulin pump user
 Object - Hide the pump from view
 Opponent - One's own chronic illness, task-specific clothing/movement requirements, placement of inset, the pump (blocky), bust size, women's fashion trends, beauty standards
 Helper - Bra, bust size, tights/bike shorts, pump bands, remote-operated blood-testers, specialty under garments, pump clips, private spaces (such as bathrooms), pump slip (for a dress)

This second Actantial Model based on *f(Hiding the Insulin Pump)* is very clearly managing positions within an important semiotic square concerning “visibility”:



Visibility applies to both the pump as an object in its own right, and as a signifier of something potentially more problematic. This function, then, while clearly concerned with visibility and moving from either right-position to either left-position (preferably toward “Hidden”), can in fact be broken down even further to more of a base function being filled by the act of “hiding”. The act of hiding is actually only important because of the social function it provides the actor. In this case, the act of hiding the pump allows “Diabetics” to feel or pass as “Normal” or “Non-Diabetic”. Thus, this function works off of a set of social norms represented by the following semiotic square:



This square provides us with some of the framework to construct a deeper-level function at play within the function of Hiding the Pump as follows:

f(Insulin Pump User Feeling/Passing as “Normal” or Non-Diabetic)
 Sender - Social norms of health/able-bodiedness
 Receiver - User/other social interactors

Subject -	Insulin pump user
Object -	Hide the pump
Opponent -	One's own chronic illness, placement of inset, the pump (blocky), bust size, women's fashion, beauty standards
Helper -	Bra, bust size, tights/bike shorts, pump bands, remote operated testers, specialty under garments, pump clips, private spaces (such as bathrooms), pump slip (for a dress)

It is the desire for an outwardly defined sense of “normalcy” that drives the surface function of hiding the pump in the first place. Without this desire, our analysis would be complete after *f* (Minimizing Insulin Pump's Unwanted Impact on Day-to-Day Life). Thus, in the section that follows, I will trace this desire and other passions, as well as the corresponding modal progression through TeeOneDee's narrative program.

Modalities and Passions

Accomplishing the functions outlined above—by either the Addresser prior to the speech event or by the Addressee following their instructions—takes place within a particular modal progression that can be modeled in three units and two steps as follows:

(Causing-to-be + Having-to-do)	
+	
(Wanting-not-to-do/be (or Not-wanting-to-do/be) + Not-being-able-not-to-do/be)	
V	V
(Knowing-how-to-do + (an implied) Being-able-to-do/be)	

In the first modal position, the insulin pump user is constrained by biological processes within their body that causes them to respond in a particular way. These processes can be interpreted as outside forces acting on the subject's state or perhaps essence, even though those forces physically come from within the subject's own biological self. Those constraints (the causing-to-be) thus require particular actions from the subject in order to deal with that altered state (the having-to-do). As such, the first units of the first step above combines both Virtualizing and Realizing Modalities (Greimas 1976: 121-139).

In the second unit of the first step, the subject experiences stress- and anxiety-inducing contradictory modalities simultaneously with the first unit. Though the subject is constrained to both be

and do (be: Diabetic, do: treatment), the subject clearly does not want to be or do either of those things—hence, why would TeeOneDee spend the time to record and upload this instructional video, or even more foundational, why would TeeOneDee attempt to “wear” and “hide” her own pump in the first place?

These contradictions lead the subject to seek relief from the tensions in some form or another. Enter: TeeOneDee’s advice. By watching this and other similar instructional videos, the subject can obtain certain functional knowledge leading them to actions intended to alleviate that tension. But, because the initial state in the first unit of the first step combined both a subject of *doing* and a subject of *state*, the resolution provided by these instructions changes both the subject’s actions and the subject’s state. Considered in a social context, this shift in state has implications for one’s sense of self, marking an important shift along the semiotic square above from “Diabetic” to “Normal”.

As some of the language I have used in this section implies, the tensing and relaxing that accompanies this modal progression points toward a correlating shift in passions (Greimas 1981: 148-164). When considered within the context of the lived social experience of the diabetic-pump-using subject, unit one of part one in the modal progression above (Causing-to-be + Having-to-do) often incites uncomfortability—both in the subject and (if only perceived by the subject) potentially in other social actors as well. This is rather common when these types of constraints construct non-normative social positions generally, and could potentially be extracted and applied on the basis of race, gender, sexuality, class, age, or any number of social identifiers. That uncomfortability can also take the form of awkwardness, defined as “embarrassing”, “inconvenient”, and even “untoward” or “unfavorable” (OED 2015).

As unit one comes into narrative contact with unit two, thus creating the first part of the modal progression, the contradictions between them turns uncomfortability and awkwardness into tension, stress, nervousness, and anxiety. As I have outlined above, it is this anxiety that leads individuals to search for something to alleviate that tension and anxiety, lest they intensify to the point of debilitation.

Once the relieving agent is introduced to the narrative program, the anxiety produced by contradictions of state and doing is transformed into a relieved and empowered state, along with placid

perfunctory action. This simultaneous transformation is particularly meaningful, considering the subject's lack of power implied in unit one and intense disquiet when paired with unit two. Thus, we can re-map the modal progression with passions as follows:

(Causing-to-be + Having-to-do)	—	Awkwardness
	+	
(Not-wanting-to-do/be + Not-being-able-not-to-do/be)	—	Anxiety
V		V
(Knowing-how-to-do + Being-able-to-do/be)	—	Perfunctory Empowerment

It is here, in the paired utopic spaces of anonymous internet videos and the subject-body, that both narrative functions can be resolved in obtaining the object of value. Once insulin pump users have the Competence as prescribed in TeeOneDee's video, they are able to "pass" into a normative state—both in their own self-perception and in the ways others can and cannot see them—and in so doing, their use of a once-cumbersome medical device becomes second nature.

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