

An Autoethnographic Perspective on Type 1 Diabetes Burnout

A Research Paper submitted to the Department of Engineering and Society

Presented to the Faculty of the School of Engineering and Applied Science

University of Virginia • Charlottesville, Virginia

In Partial Fulfillment of the Requirements for the Degree

Bachelor of Science, School of Engineering

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Spring, 2022

On my honor as a University Student, I have neither given nor received
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for Thesis-Related Assignments

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Introduction to Diabetes Burnout

Of all the major health conditions that affect people in the United States, one of the most profoundly impactful conditions on its affected population is type 1 diabetes. 34.2 million people in the United States have diabetes (*A Snapshot*, 2021) and this prevalence is projected to increase to 60.6 million by the year 2060 (Lin et al., 2018). The two most common disease states are type 1 (T1D), accounting for 5-10% of diagnosed cases, and type 2 (T2D), accounting for 90-95% of diagnosed cases (*A Snapshot*, 2021). Both disease types cause chronic high blood sugar concentrations, also known as hyperglycemia, within blood vessels of the body, and sustained hyperglycemia increases the risk of blood vessel death and a myriad of complications including heart disease (Kannel et al., 1990), blindness, nerve pain, kidney disease (*A1C Variability and the Risk of Microvascular Complications in Type 1 Diabetes | Diabetes Care*, n.d.), and cancer (Smith & Gale, 2009). There is an important distinction between the main types of diabetes, being that T1D is defined by an autoimmune response resulting in loss of insulin-producing pancreatic beta cells (*Type 1 Diabetes - ScienceDirect*, n.d.), whereas T2D is defined by increased insulin resistance in which insulin is still produced autonomously by the body but not in adequate amounts to maintain healthy blood sugar levels (Klöppel et al., 1985). The former requires exogenous insulin delivery, either in the form of injection or an insulin pump, constant surveillance of one's blood glucose level, and the knowledge that one mistake, either in the form of a missed insulin injection or the delivery of too much insulin, could result in dire consequences for the patient.

T1D patients often experience overwhelming feelings of exhaustion and frustration in response to the challenging requirements of blood glucose management, defined by the term “diabetes burnout.” Burnout is listed by 66-74% of healthcare providers as one of the most

common psychosocial complications of diabetes (Abdoli et al., 2021), yet there is no standardized treatment option for diabetics who suffer from burnout symptoms. The manifestation of these symptoms often results in compromised levels of diabetes management (Lee, 2012), thus novel remedies for burnout must be investigated. In the following sections, an exploration of the research question, “What are societal, physical, and emotional consequences of diabetes burnout, and what are the potential solutions for those who struggle with this condition?” will be conducted through the framework of wicked problems. This framework will be utilized to emphasize the scope of diabetes burnout and its main contributors. As someone who has lived with T1D for 16 years, I will also analyze diabetes burnout through my own experiences. The analysis conducted here will propose novel alternatives to patients who struggle to live with a difficult disease and improve their diabetes management.

Research Question and Methods

Keywords: Type 1 diabetes mellitus, wicked problems, biotechnology, diabetic complications, diabetes burnout

Under the framework of the wicked problem, testimonies from T1D patients and healthcare providers will be analyzed and compared to identify any commonalities, because the relationship between T1D patients and healthcare providers has been shown to contribute to burnout. A collaborative strategy to wicked problem framing is used, adopted from the work of Dr. Nancy Roberts (Roberts, 2001). Patient testimonials are explored further to determine whether more stakeholders are involved, and a high-level overview of each stakeholder perspective is summarized. The goal of this approach is to find common ground between different stakeholders. One suspected area of common ground among all stakeholders is the

desire for each patient to improve their BG control and subsequent quality of life, but this common goal requires a deeper understanding of challenge areas for the patient. Another key method of analysis used is autoethnography, a technique allowing myself as the author to reflect upon and document personal experience as a diabetic; interrogating cognitive, performative, or inter-actor relationships between myself and the key stakeholders involved in diabetes burnout.

Background on T1D Physiology and Burnout

To elaborate further on the emotional and mental condition of someone affected by diabetes burnout, it is necessary to examine my personal experience in living with T1D, as testimonials by affected populations may offer a new perspective. A fundamental trait of a newly diagnosed diabetic is a feeling of discomfort that they can no longer fit in with everyone else, and I believe this is a source of burnout. For myself, this feeling manifests itself in different ways and directly results from the reality of living with T1D: I have to be conscious of my blood glucose (BG) level, I have to make unique decisions about nutrition, and I have a dependence on technology.

Living life post-diagnosis requires knowing what my BG concentration is because a concentration that is too low or too high can be life-threatening. I use this number to decide when to eat, how much insulin to inject for a given meal, when to exercise and stop exercising, and whether I can go to sleep safely. Maintaining tight control is crucial to decrease the risk of complications such as diabetic retinopathy, a condition indicating damaged blood vessels in the retina that increases the risk of blindness, and heart disease (*Diabetes Complications*, n.d.).

In terms of nutrition, I limit the amount of carbohydrates I eat and insulin I inject so that I have a lower risk of high BG levels (hyperglycemia) and low BG levels (hypoglycemia),

respectively. This dietary change has improved my BG control substantially, but it has made my social life much more challenging.

My philosophy on diabetes is to have BG as close to physiological, or non-diabetic, levels as possible, but this goal comes with a dependence on diabetes technology. Wearable diabetes technology like continuous glucose monitors improve BG control significantly (Capon et al., 2017), attributed in part to alarms on my phone for high and low BG that allow me to correct BG quicker. Staring at my BG displayed on my phone screen can be exhausting over time and I no longer feel safe going anywhere without my phone nearby.

Overall, the knowledge that simple choices can have serious consequences and that I need to be focused on my BG constantly is sometimes hard to handle. The experiences I have described are not unique to me, and the feelings of exhaustion and exclusion among all T1D patients are sources of burnout that need to be explored further.

Before proposing novel solutions to diabetes burnout, it is important to contextualize the main contributors of burnout and current treatment solutions. A 2018 study by Abdoli et al conducted a qualitative analysis of diabetes blog posts that documented feelings of diabetes burnout and distress. Of these posts, common keywords attributed to diabetes burnout were the “massive responsibility” and the “relentless amount of work” done in managing diabetes, “draining pressure” from healthcare providers to improve BG management, an ongoing “battle with insurance” for American bloggers, and a “hesitancy to ask for help” to improve their condition (Abdoli et al., 2018). These factors are both personal and systemic, ensuring that it is challenging for physicians to treat burnout, especially with an approach that doesn’t take individual conditions of each patient into account. Abdoli et al conclude that the study provides meaningful information that will hopefully improve the quality of person-centered diabetes care

and quality of life for T1D patients, inferring that improving those characteristics is the key to combating burnout. The wellbeing of each patient is dependent on internal factors such as their ability to improve BG management and lower the risk of diabetic complications, as well as external factors such as the patient-physician relationship and the access (or lack thereof) to medication. The many actors that have a role in diabetes burnout thus increase the scope of the problem—therefore, diabetes burnout will be analyzed later through the framework of a wicked problem.

STS Framework: Diabetes Burnout as a Wicked Problem

Framing diabetes burnout as a wicked problem enables the researcher to pose burnout as a complex issue with many parts which must be understood in order to offer a solution. German design theorist Horst Rittel and American urban designer Melvin M. Webber introduced the framework of the wicked problem in 1973, defining it as a problem, usually social or cultural, that is challenging or impossible to solve either because not enough is understood about the problem, the number of stakeholders involved, the number of varying opinions, the economic burden, or the impact of these problems with other problems (Rittel & Webber, 1973). Since wicked problems are generally difficult to define and open to interpretation, the topic of diabetes burnout can be used as a model under this framework.

With so many stakeholders involved, framing the problem as a “wicked problem” will help acclimate the reader to all of the involved actors and streamline the process of analysis. However, the theme of wicked problems has been critiqued in the past for its ineffectiveness in proposing solutions for the problem at hand (Turnbull & Hoppe, 2019). Nick Turnbull and Robert Hoppe, professors of social science and policy and knowledge and policy respectively,

argue that naming a problem as “wicked” is not conceptually coherent in the context of policy problems. They argue that problems should be framed from their “problematicity” and not from “wickedness”. The two scholars define problematicity as the distance between those who question a policy problem, and they argue that this argument constitutes a superior perspective to that of wicked problems.

While wicked problems are commonly used in the realm of public policy, and it is this realm that the framework is sometimes criticized within, wicked problems can still be a meaningful way to emphasize the importance of solving such a problem and attempting to consider all areas of complexity. In the Journal of Palliative Medicine, Dr. Vyjeyanthi Periyakoil draws a distinction between tame problems, those which can be solved using linear methods of problem solving, and wicked problems (Periyakoil, 2007). Periyakoil continues by explaining that different stakeholders within a wicked problem often have radically different ways of understanding the problem at hand and approaching a solution. It is with this explanation that the framing of diabetes burnout as a wicked problem can finally be understood. Key stakeholders include healthcare providers, friends and family members, insurance companies, and the T1D patients themselves. These actors all have different perspectives by which they view a patient’s burnout, and an analysis that summarizes each stakeholder’s perspective will piece all relevant parties together and clarify potential palliative care to those who struggle with burnout.

Results and Analysis

Summary of Results: The following section analyzes the different stakeholders involved in T1D burnout. An optimal relationship between T1D patients and each stakeholder is outlined. A stakeholder is an entity that has proven, through literature or my personal experience with

T1D, to contribute to burnout. These stakeholders include physicians, support systems for patients, cost contributors, biotechnology companies, and the psychological condition of the patient themselves. A technique for physicians is described to elevate their relationship with T1D patients by approaching treatment collaboratively, so that patients are adequately informed on all aspects of diabetes and a treatment regimen can be prescribed according to one's unique lifestyle. The importance of finding an informed support system is described. An analysis of the state of financial stress in T1D patients is conducted, and an establishment of unrestricted affordable access to insulin is suggested. The need for biotechnology companies to ideate novel technologies in a patient-centered framework is emphasized. The internal struggle of BG management within the patient is explained, and the necessity to gain information on diabetic complications is summarized.

Overview of Stakeholders: One of the reasons why the problem of diabetes burnout is so wicked is because of the stakeholders involved. These stakeholders include the healthcare providers of T1D patients, a support system usually consisting of friends and families of patients, contributors to the cost of modern diabetes care, biotechnology companies that produce devices to improve diabetes management, and the T1D patients themselves.

Healthcare Providers: Healthcare providers of T1D patients, just like other types of healthcare providers, explain diagnoses, monitor patients on a consistent basis to assess health and fitness, write and refill prescriptions for medication, and deliver advice to patients based on verified strategies of success. For many newly diagnosed T1D patients, physicians are the first source of information in diabetes management, because T1D is poorly understood by unaffected parties. For this reason, patients are sometimes likely to blame or praise their physician for everything related to diabetes treatment. In the case of T1D, successful management is achieved

by reaching consistent BG levels that fall within a healthy range so as to avoid severe complications of diabetes and to increase longevity. The strength of a patient-provider relationship can make or break successful BG management, and a relevant example of this comes from personal experience.

Most T1D diagnoses occur in childhood, before the age of 14 (Patterson et al., 2014)), and I was no exception. T1D is sometimes referred to as juvenile diabetes for this reason. Accordingly, young children with T1D primarily seek advice from their parents, who are taught diabetes management basics by their child's physician. Both parents and physicians of children with T1D have to be careful when giving information to their child about T1D. I was five years-old when I was diagnosed with T1D and, understandably, I was not given any information on diabetes complications, nor their severity. I learned simple information that I could understand, like the fact that food generally raises BG and that I need to inject insulin to lower BG. To me, BG was just a number that appeared on a meter after I pricked my finger and fed blood into a test strip that transports blood to the meter. This testing method was the most common for T1D patients to receive BG information before the recent invention of continuous glucose monitors. It wasn't until 13 years later when I began studying biomedical engineering and reading on the topic independently that I became aware of all of the risks posed by poor BG management, after which I greatly improved mine. If I was informed about the consequences of not taking care of myself from a much younger age, my health might be better today. People with chronic illnesses deserve to know the worst-case scenario. There is a balance between protecting the innocence of young people and withholding crucial information, and physicians should be aware of this balance.

This goal of successful management is much more attainable with guidance from a diabetes expert, and positive patient-doctor relationships have long been associated with better metabolic control of diabetes (Viinamäki et al., 1993). The terms of a positive patient-doctor relationship and what dictates a successful experience are ultimately up to the patient themselves. After the year following diagnosis, T1D patients typically only see their physician 1-4 times a year, so it is possible that patients will seek guidance after months of self-management in between visits. A lack of accessibility to physician guidance is a contributing force to burnout (*The Psychological Impact of Type 1 Diabetes*, 2021), and office visits can be extremely valuable to patients if they are conducted in the best interest of the patient. While physicians broadly decide the best course of action for treatment, the nature of T1D as a life-threatening chronic illness requires that patients be knowledgeable, responsible, and diligent in their management. For this reason, physicians may have more success in a patient-centered, collaborative approach rather than a directive one (Heisler et al., 2003). Using patient data from the time in between visits and asking questions according to the level of management is one method of approaching a collaborative relationship. A collaborative approach to the patient-physician relationship allows the patient to possess all necessary information on T1D in order to live healthily and according to their own lifestyle.

My Support System: Requirements of BG management can be exhausting and overwhelming to T1D patients, which emphasizes the need for a strong support system. As patients begin to understand their chronic illness and prioritize their health, dynamics of relationships with close ones are subject to change (Monaghan et al., 2015). A network of family, friends, behavioral health experts, and other T1D patients is incredibly important for patients so that they are not alone in their BG management.

One of the most difficult aspects of life with T1D is that diagnoses happen more frequently in children than in other age groups. At an age where children are only just starting to interact with their peers, the diagnosis of any autoimmune disease can disrupt childhood and result in upheaval from their previous lifestyle. I was often tremendously frustrated by the fact that I could not “just be normal” like all of my peers and be able to live without the constant worry of variable BG values. My mother empathized with the intense emotions I often experienced as a result and became my first support system. She asked questions to physicians about T1D and tried to understand my lived experience, which I always appreciated. One word of advice she gave me is that I need to someday find a partner who understands T1D and cares for me enough that they can completely manage everything for me when I am upset or otherwise unable to do so myself. I was experiencing burnout myself before I even knew the term, and her words have stayed with me. Whether it is a parent that can sometimes take the reins of BG management during childhood, or a partner during adulthood who will do the same, this level of support is sometimes necessary. An intense period of diabetes burnout leaves patients feeling exhausted, detached, and powerless (Abdoli et al., 2020), which can be alleviated with a temporary caretaker.

Friends of T1D patients also play a crucial role in preventing and coping with diabetes burnout. Patients must ensure that their close friends can appreciate the scope of T1D and its associated risks so that patients feel safe and understood. I have found this quality in my close friends in engineering school at the University of Virginia, where the ability of engineering students to conceptualize and design solutions to difficult problems has contributed to my friend group being able to comprehend my condition. After learning about the complications of diabetes, I tightened my glycemic control by eating a diet very low in carbohydrates. If done

carefully, this diet allows for exceptional BG control and low rates of adverse events (Lennerz et al., 2018). I learned this new approach to T1D through a book, which I requested that my friends read a portion of. In turn, they have been incredibly patient with and supportive of me. Providing information about T1D that unaffected parties can understand is the first step a patient with T1D can take to surround themselves with a knowledgeable support system.

Cost Contributors: The financial impact of T1D in the United States is inconceivably high to most. According to a 2020 analysis on the lifetime financial burden of T1D in the United States by Sussman et al, diabetes (both types 1 and 2) accounts for \$237 billion in direct medical costs per year, or 7% of annual health expenditure in the United States (Sussman et al., 2020). Diabetes health expenditures are highest of any chronic illness including cancer (5% of annual health expenditures) and heart disease or stroke (4% of annual health expenditures). Sussman's model specifically focused on T1D expenditures, and projected that T1D patients in the United States spent \$211 billion more in lifetime cumulative cost than nondiabetic control subjects, even after taking into account that the average life expectancy of a T1D patient is nine years shorter (70.9 years) than that of nondiabetic subjects (79.9 years), illustrating a very high economic burden for families of T1D patients. Why is this number so high, especially compared to every other chronic illness in the United States? T1D patients require lifelong exogenous insulin delivery, a medication that has grown 240% in price from 2015-2017 compared to the growth from 2005-2007 (Taylor, 2020), all while prevalence of T1D continues to increase. Exclusivity in the insulin market promotes high product prices and restricted access to innovative treatments to both patients and upcoming competitors. Further, legislators in the United States have enacted very few regulations on insulin prices. This lack of regulation adds extreme financial stress to patients who already experience human suffering in the form of increased risk for cardiovascular

disease, amputations, end-stage kidney disease, and blindness after years of sustained hyperglycemia. Patients unable to afford their medication ration insulin until they can afford to refill their prescriptions (Fralick & Kesselheim, 2019). Consuming a meal as a T1D patient without taking adequate amounts of insulin results in extreme hyperglycemia, which, if not corrected, can result in diabetic ketoacidosis and death. When considering the fact that up to 60% of exogenous insulin users lack secure access to affordable insulin (Beran et al., 2022), it should be clear that the problem of affordable access is immense and must be immediately addressed by authorities who are able to influence healthcare legislation going forward.

Biotechnology Companies: It has been 100 years since insulin was first manufactured and prescribed to T1D patients. Before this incredible scientific achievement, T1D diagnosis was equivalent to a death sentence. Researchers and scientists who specialize in technology for T1D patients have greatly increased longevity and quality of life for all diabetics (Miller et al., 2012). As innovation advances in the realm of biotechnology, researchers can now add convenience to functionality for T1D medical devices.

As a child, I experienced a lot of difficulty becoming comfortable with the fact that I was different from others. I could always do everything that my healthy peers could, but not without planning ahead. I always carry a medical kit with insulin pens, glucose test strips, and needles everywhere I go. For a short time I explored the possibility of using an insulin pump, a device attached to the body that includes an insulin cartridge and a phone-like display that allows the user to decide the insulin quantity. Insulin pumps provide patients with the convenience to inject insulin without pulling out syringes in public spaces, and I assure the audience that this action can be extremely jarring. However, these pumps are expensive, the tubing from an insulin pump is visible, patients must carry a waistpack that holds the device, and site changes are required

every 48-72 hours to reduce the risk of an immune reaction at the pump insertion site. For these reasons, and because I am able to manage BG without the assistance of an insulin pump, I continue to use manual daily injections (MDI). Biotechnology companies continue to produce discreet devices for T1D patients. The Omnipod DASH™ insulin management system uses Bluetooth that allows users to choose insulin delivery from their phones and transmit it directly to the pump site without tubing (Ly et al., 2019). Innovations like this introduce convenience to the diabetic experience where it did not exist before. Next to a cure for diabetes, the ability for diabetics to experience life without unnecessary obstacles is the best gift that can be given. These companies have potential to improve quality of life substantially once a patient-centered approach to technology is put into place.

T1D Patients: The previously outlined stakeholders all contribute to the condition of T1D patients. Physicians enable patients to make healthy decisions and avoid complications, a support system ensures that the patients are not alone in BG management, legislators and insurance companies hold power in their ability to dictate cost for diabetes medication, and biotechnology companies hire experts to develop devices that profoundly impact the lived experience of T1D. There is also a psychological component to diabetes burnout that causes both BG management and morale to decline. An analysis of diabetes burnout-focused blog posts written by T1D patients was conducted by Abdoli et al in 2019, and its results illustrate the psychological struggle of T1D by providing common themes of diabetes burnout. These themes are: a detachment from diabetes care, the demanding life of diabetes, the struggle to achieve perfect BG numbers, life events that act as burnout catalysts, and overcoming burnout being equated to climbing out of a difficult hole (Abdoli et al., 2019). From these results, the connection between stakeholders and themes of diabetes burnout cannot be determined. It is likely not only one, but

multiple stakeholders, that each blogger had in mind when expressing their feelings of frustration. Sometimes burnout stems from an internal struggle—the constant thought of vigilant BG management that never stops, never pauses, and can never be ignored. Relationships with external stakeholders can and should be optimized, but it may prove to be more difficult to optimize the condition of the patient while dealing with their T1D. In my life with diabetes, the best decision I ever made was to start reading about the worst-case scenarios of BG management and the subsequent consequences.

Limitations and Future Work: The analysis conducted above is a culmination of 16 years of personal management with T1D, as well as four years of biomedical engineering education, a field that studies the impact of complex health problems and the approaches to improve them. Wicked problem framing assisted in this analysis by dissecting each relevant stakeholder and providing suggestions to tackle root problems I have identified through personal experience and literature. Until all of the problems that T1D patients experience are addressed, it will still be meaningful to continue researching the topic of diabetes burnout. A main limitation of this project was time, being that burnout is such a difficult topic to understand and that any solutions are obsolete without taking into account all of the contributors that lead to burnout. Since physicians are the first to come into contact with newly diagnosed T1D patients, there needs to be a standardized approach to informing patients about all aspects of life with diabetes, because I believe that information is the best antidote to burnout. Experts should continue to research the best way to approach this in the future.

Conclusion

The permanent solution to diabetes burnout lies in the cure to diabetes. However, the relationship between T1D patients and relevant stakeholders have been analyzed in this work. Physicians must collaboratively approach T1D patients, enabling the patient to gain all relevant information on diabetes and prescribe an insulin regimen according to their personal lifestyle. Patients should never underestimate the power of an informed support system built of friends and family members. Cost contributors, those who dictate prices for T1D medication, must re-evaluate current legislation on prices so that T1D patients can access affordable medication. Biotechnology companies, as they strive to release cutting-edge diabetes technology, must adopt a patient-centered approach to their ideation in order to optimize convenience after functionality. Lastly, patients must learn about the consequences that inadequate BG management can cause. Fear is an excellent motivator, and the preservation of one's own health is the most powerful key to a long and happy life.

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