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## Heightened Technology in the Care of Type 1 Diabetes: An Ethical Symbiosis?

### Cover Page Footnote

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# HEIGHTENED TECHNOLOGY IN THE CARE OF TYPE 1 DIABETES: AN ETHICAL SYMBIOSIS?

By Susanna Larsen

## I. INTRODUCTION

I've grown up through endocrinologists' offices, worried over middle school sleepovers while waiting for lab blood results, wondered whether my friend would ask me to the winter formal while being questioned on the trends of my blood sugar numbers, and explained away my doctor's latest concerns with stress over SATs. With five shots a day for over six years straight and countless blood checks, my days were always waiting for the next injection, the next blood sugar, the next meal I needed to dose for. Doctors, nurses, and educators preached that my burnout would dissipate once my health was stable, and I could begin using insulin pumps and glucose monitors. Because of how information was presented to me throughout my middle school years, I envisioned high school and college students with diabetes using insulin pumps and blood monitors, all able to eat whenever they wanted, being discreet about blood checks, and not feeling constantly overwhelmed. Finally, the day came when I got my Omnipod insulin pump and Dexcom G6 monitoring system. While devices have made certain diabetic management aspects more manageable, they fall short of what I was led to expect during my earlier doctor visits. These technologies come with unique sets of challenges, can worsen preexisting problems, and do not adequately address a variety of obstacles commonly experienced by diabetics such as burnout and supply reorders.

Type 1 diabetes is an autoimmune disease that impacts around 1.6 million Americans and typically begins in adolescence (JDRF). While there is no cure, treatments have vastly improved in the last century. For example, insulin, which once was extracted from animals for human use, is now created synthetically in a lab, and this is not the only recent advancement. Blood monitors can connect via Bluetooth and provide constant records, and insulin pumps are becoming increasingly intuitive of users' needs. The development of closed-loop systems allow insulin pumps and blood monitors to communicate; this teamwork removes the patient from necessarily making every decision and has the insulin pump automatically correct for swings in blood sugars. Closed loop is a medical system where the technology inter-communicates to automatically react to blood sugars and administer insulin without human interaction.

These technologies impact the treatment for diabetics and affect other aspects of their lives as well. Technological interventions are not unqualifiedly beneficial, though, and while diabetic technologies can be positive developments, the potential negative side effects – especially on mental health – should not be ignored. Already, diabetics are at a higher risk for “diabetes distress, depression, anxiety, and disordered eating” (ADA). Many people with chronic conditions struggle constantly with mental health, and technology may both favorably and adversely affect mental health issues.

Introducing heightened technology in care brings its own set of moral questions. Is it ethical to ask diabetic patients to surrender their control to technology? These electronics come with unique requirements and costs, but it remains an open question whether the benefits for patients outweigh the burdens. Should diabetics be required to prioritize their physical health with technology as the field suggests? I argue that the current medical field requires harmful prioritization of physical health over mental health and needs to be remedied. In the end, we

should consider the ideal ethical scenario for introducing complicated technology into the care of Type 1 diabetics. For clarity, whenever I refer to “diabetics” or “patients,” I will be commenting solely on Type 1 diabetics. Additionally, my focus will be on the impact of medical technology around the period of adolescence, anywhere from older children to young adults, which I will generally refer to as “youth.” I will also refer to continuous glucose monitors (CGMs), usually used in tandem with insulin pumps.

In this paper, I will discuss the ethical impacts of technology on the view of self, mechanical requirements, and health priorities for Type 1 diabetics. Following that, I will outline some possible solutions to these ethical problems and conclude my thoughts.

## II. SELF-WORTH

Type 1 diabetes commonly occurs in teens and young adults. At these times of their lives, interests are explored, identities are investigated and developed, and future endeavors are researched. Adolescence and young adulthood are both paramount periods during which an individual learns to process the world around them and to perceive themselves. Increasingly, young diabetics internalize their diabetic healthcare as their sense of self. This is influenced by children’s early education experiences with school systems using letter grades and point systems. The kids with straight As are considered ‘good students,’ and children incorporate this label into their self-perception. This grade system is comparable to the hemoglobin A1c test for diabetics – a scale from about 5 to 13 that represents their estimated average glucose levels (Redondo et al., 2021). Physicians and care teams always have a target A1c for the patient, and when not met, increased effort goes into lowering the patient’s A1c. Much like rewards from grade points, when a patient receives an A1c closer to their target, the parents and medical team will be

pleased, thus incentivizing the patient to focus on whether or how their health effort manifests itself as a “good score” that satisfies the authority figures in their life.

A1c rates have lowered in recent years due to technological advances like CGMs and insulin pumps, but still fewer than 15% of diabetic youth actually reach their target A1c (Eilander, 2016). Technology has helped improve A1c scores, but it has not helped patients avoid affiliating their health scores with their self-worth. While doctors specify that A1c scores are “just a number,” and are individualized, there still needs to be a shift. Healthcare providers should report results less judgmentally and more factually to discourage harmful long-term connotations with scores. These harmful connotations can include a sense of inadequacy, fear or guilt associated with disappointing authority figures, or taking responsibility for variables outside of the youth’s control. Guardians and patients receiving these A1c scores and other diabetic results will be in a better position to separate the diabetic’s inherent self-worth from their current physical health. While healthy lifestyles should be sought, emphasis on A1c scores tend to cultivate a Pavlovian situation for the young patients. Low A1c scores that achieve a goal standard are usually followed by parents and physicians congratulating their diabetic child or patient and sometimes rewarding them. The patient is trained from these scenarios to view lower numbers as ‘good’ and as direct evidence of their effort. This means that with less than ideal results, the patient is pushed to rectify what is causing higher numbers and improve their score. The diabetic may take this to mean that their hard work is not enough, and may compare themselves to the hypothetical, “ideal diabetic” whom the target score represents. This problem existed before heightened technology was introduced, but automations have not made any sizable improvements to the scenario, only making it easier to calculate and constantly report

average scores. Reporting is now unceasing and substantially more oppressive in the patient's daily life.

### III. TECHNOLOGY REQUIREMENTS

The average diabetic spends \$9,600 a year solely on their diabetic supplies, which is 2.3 times more than what a non-diabetic spends for their entire medical expenses (ADA, 2018). The new technology developments of improved CGMs and insulin pumps only add to these costs. Are those charging steep prices for these innovations acting immorally? Insulin pumps and CGMs are technically unnecessary but greatly improve diabetics' medication reaction time and combine various supplies into consolidated devices. Is there a positive right to diabetic technologies? In other words, should diabetic technologies such as CGMs and pumps be available and supplied by the government when the private sector does not supply them? Or should only the bare minimum of tools required for diabetes be offered free of charge or subsidized?

Another underestimated cost of technology is its conspicuousness. Diabetic pumps and CGMs have grown smaller in recent decades, but they are still noticeable with their bulky obtrusions, tangling tubes, and constant beeping. Additionally, their sound systems are designed to be unignorable. These technologies sound alarms that cannot be silenced and are hard to hide with their clinical aesthetic juxtaposed on human skin. While physically standing out may seem trivial when given the alternative (worsened quality of health), the aesthetic design of health technologies can have a negative impact on the mental wellbeing of the patient, who views them as further evidence that they are misfits. Society has become more open towards body modifications or aids, such as tattoos, piercings, or hearing aids, but diabetic technology has yet to be normalized. Tattoos and piercings cause the individual to stand out, yet they are voluntarily

chosen, unlike medical technologies. Hearing aids resemble diabetic technologies in their non-elective quality, but have become so discrete they be confused with common earbuds. In a way, they are normalized, not by their own virtue but because they resemble an entirely separate normalized object. Unlike hearing aids and earbuds, there have been no trends in the able-bodied community that involve mechanical, non-limb pieces attached. Attitudes towards diabetic technologies – or other conspicuous medical devices – still view the individual with morbid curiosity or pity. In a time when youth commonly try to avoid alienation from their peers, being outed by their prominent technology is a bitter pill. Youth do not want to feel defined as the ‘diabetic kid’ or asked invasive questions about sensitive topics, just as other aspects of identity should only be shared when someone feels secure.

The last big shift related to technology is information sharing. Records are now being sent from the technology’s memory, stored in clouds or on hard drives, and shared with doctor offices, insurance companies, and more. What once was a more private, singular documentation process has now become a team effort for better and for worse. This allows for physicians to view exact dates, trends, and data more easily. Information can be compiled to help improve the patient’s care and for health companies to compose business statistics. This means that more groups can comment qualitatively on the patient’s unique health, exacerbating patients’ concerns about self-worth. Groups such as physicians, practitioners, healthcare decision makers, and researchers all can gain access to diabetic data. Subsequently, when providers and businesses are not familiar with the patient’s unique background, situation, and healthcare needs, the risk for dysregulated comments and unrealistic treatment plans increases exponentially.

In my youth, new doctors unfamiliar with my exact type of diabetes critiqued my blood sugar trends, commenting that my numbers would display improvement if I simply put in more



effort. Their insensitive comments undermined my perception of any progress I had made and worsened my burnout symptoms. Regardless of whether their remarks were true, their comments resulted in increased self-condemnation and resentment of any assistance they might have been able to offer.

#### IV. PRIORITIES

Type 1 diabetes is described as a “24/7 disease that requires constant management” (JDRF). Yet, even with a strict, consistent regimen, life-threatening glucose levels are still to be expected. It is also one of the few diseases where the patient is the one most actively involved in managing their own disease. Alongside believing their health is linked to their sense of self, diabetic youth also view prioritization of physical health as a moral imperative (Ketchell, 2016). Youth are busy with hectic schedules, yet they are expected to set aside adequate time and energy for their diabetes.

CGMs and insulin pumps can lessen the burden of time, but they do come with their own problems. As discussed previously, these technologies are conspicuous, costly, and release data to healthcare and insurance companies. On top of these, they can be difficult to access. Even with insurance coverage, patients require doctor’s appointments for set up, approval from insurance companies, and long timeframes for all these steps to happen. In exchange for hopefully easier day-to-day care, the patient or their family must keep up with all the paperwork and requirements of their technology. These include frequent doctor appointments for paperwork upkeep, programming revisions to maintain accurate dosage, and recurrent supply reorders.

## V. POTENTIAL SOLUTIONS

Proponents of feminist approaches to bioethics claim that individuals are not always able to advocate for themselves, and should not be compared to society's status quo (Lindemann, 2019). Adolescents are especially ill-equipped to handle total lifestyle changes on top of managing their schoolwork, social life, and more. Even young adults are caught up in secondary schooling, handling bills, and managing life decisions. Life gets complicated, and healthcare regimens slip through the cracks in stressful situations.

Feminist ethics recognizes the importance of the distribution of power, usually masculine power but also applicable to able-bodied advantages (Scully, 2023). Diabetic youth can feel disempowered by the earlier consequences discussed (i.e. unavoidable attention requirements, time obligations, feelings of judgment, etc.). Jackie Leach Scully explains that, historically, the “‘failure’ of women’s embodied experience to fit patriarchally defined gender stereotypes” was viewed as a problem only remedied via medical treatments (182). I argue that a similar case is applicable for the diabetic community: diabetic problems should not be automatically prescribed medical or technological remedies. While some technological changes are necessary, social shifts are equally vital and arguably the better remedies for some problems I have discussed. One such problem requiring social remedy is the language use and delivery by medical professionals. As previously outlined, the contemporary diabetic medical field conflates facts and numbers with moral judgements or character traits. Medical institutions and learning facilities should implement a shift in their medical professionals’ responses. Blood sugar data and insulin doses should be presented factually – avoiding rewards or punishments based on chance biology. Requiring the medical staff to avoid charging diabetic results with emotions will ease the pressure on patients internalizing their health assessments. Technological and medical remedies

can work when added to social solutions. In this case, computer-mediated communication, such as receiving data results from a computer, would avoid any seemingly judgmental intonation or body language cues from medical staff. Although some may argue that relaying sensitive information via computer is more isolating for the patient than hearing it from a medical professional, social support systems such as family, friends, or community, are unchanged by the delivery adjustment and can act as the intimate support necessary. Social or community support systems more familiar with the diabetic patient and capable of providing individualized comfort should be primary. To enable these support systems to function as efficiently as possible, medical professionals should lessen their potential harm by reporting factually or utilizing computer-mediated communication.

Feminist approaches to bioethics, especially those focusing on disability, note that people on the “receiving end of care can [face] disempowerment, infantilization, neglect, or outright abuse” (185). While some of these experiences occur only in extreme cases, diabetic youth lacking self-confidence and empowerment are linked with worsened diabetic and overall health (Eilander, 2016). Medical situations treating the patient as a person deserving respect will avoid further weighing the patient down with feelings of pity or dependency that disabled individuals commonly face from society (184). Many Americans believe that patient autonomy, a type of empowerment, is most important. I think for diabetic adolescents and young adults, parental/adult oversight is necessary, but I do believe stringent monitoring and constant restrictions are not the ethical choice either as they diminish self-confidence and empowerment. We see the consequences of strict, authoritarian parenting on children’s development with restricting autonomy. The young person learns to hide their actions, and attempt to be self-reliant in dangerous scenarios when they should be able to trust the adults in their lives. This will likely

end in either necessitating complete distrust or cultivating mindless dependency and incapability. On the other hand, permissive parenting does not wholly benefit the child either with its inconsequential acceptance and reliance on a child's complete self-regulation (Baumrind, 1966). Allowing youth to make their own deeply hazardous mistakes can end in serious negative consequences.

Child rearing differs from the medical field, but the attitudes towards control mirror one another; children differ from adults in terms of life experiences and rational capabilities; thus they should not be expected to function as fully autonomous adults. Nor should their ability to make autonomous decisions about some areas of their lives be completely disregarded. Authoritative parenting/provision of care, not to be confused with authoritarian, acting should be implemented. Authoritative care does not base decisions solely on "group consensus or the individual's [desire]" (Baumrind 1966, 891). Instead, it is described as the "balance between pleasure and duty, and freedom and responsibility...". Margaret Olivia Little developed feminist theory to note how concepts such as gender influence our society by framing what we perceive, value, or conceptualize (Little, 1996). Disabilities, such as diabetes, can mirror gender discrimination and benefit from an application of feminist theory. Feminist theory examines androcentrism and gendered concepts. Ableism functions similarly to androcentrism; anything is labeled as otherness when it strays from healthy, able bodies. Under feminist theory, disabled individuals should not be compared to nondisabled individuals. Their unique capabilities and skills are entirely disparate and are devalued when compared to stereotypical expectations treated as the human norm. The disabled community becomes defined by their differences instead of their disability being one part of their identity (Little, 1996). Secondly, gendered concepts distort the perception and connotations of concepts; for example, historically, anything tied with

femininity was devalued (Little, 1996). Similarly, disability was historically viewed as a cosmic punishment, and today has grown to be pitied. Feminist theory holds that concepts used in conversations concerning disabilities should be scrutinized.

Feminist theory can work in tandem with authoritative care. Both assume that an individual's wishes are important, but are not the exclusive decider in determining treatment. In the medical field, we should understand that some patients are not in a state to advocate for themselves or to make decisions. Both these philosophical theories state that a responsible proxy, usually a youth's parent or their endocrinologist, ought to advise, but only reasonably limit autonomy in situations where the patient's health is significantly threatened (Little, 1996). In practical examples, a diabetic should be allowed to exercise control over their diet and activities. When their choices could result in serious harm, such as choosing not to administer necessary medications, the adult ought to step in and help. Adult intervention in these kinds of situations will enhance the diabetic youth's awareness of their own capabilities and power, avoiding worsened mental and diabetic health.

The impact of individual and collective identity is emphasized in feminist theory as well (Scully, 2023). This is how people classify themselves as "moral agents," orient what is morally relevant, or determine what is an unjust act (187). Youth being identified as a diabetic/disabled individual should be a positive, or at the very least a neutral, quality. The problem is that most Americans view disability identification as a negative trait. Disabled or chronically diseased labels are associated with naivety, vulnerability, and otherness; the label of diabetic or disabled is a problem that needs to be solved (Goering, 2015). This is a phenomenon discussed by several disability writers, such as Elizabeth Barnes, who refers to this negativity towards the disabled labels as "bad-difference." She argues that although disabilities "can (and perhaps always)

involve... a loss of intrinsic goods,” such as loss of hearing or mobility, disabilities do not equate to a loss of well-being and are instead a mere difference (Barnes, 2016). She explains that there are unique experiences that the disabled encounter that make their lives more positive and unique, opposing this to the inherent negatives normally assigned to disability. Barnes promotes a value-neutral model, allowing some aspects of disabilities to be socially constructed, but other aspects to be dependent on the circumstances (88). If society were to emphasize that disability is a neutral state and follow a value-neutral model, that would lead to a more balanced view of disability, which western culture currently lacks. Understanding and identifying one’s self brings greater empowerment, especially when shame and labeling is not placed on the individual.

Additionally, I believe access to diabetic technology needs to be considered a positive right. It is not enough to merely make available the bare minimum of supplies necessary to stay alive requiring that the patient actively seeks these resources out. In the US, many diabetic patients ‘ration’ their supplies since the government gives out only the minimum quantity of needles, insulin vials, and other supplies. If less effort were required from the patient to obtain their health supplies, more of their effort could go into conscientiously handling their health. This could be done by the government stepping in and providing supplies, or private companies being incentivized to do so with tax breaks. Patients will benefit more from these technologies while avoiding inordinate monetary costs. Lessening the financial and temporal burden allows patients to use those resources to develop a secure foundational self-image and healthy mindsets that should subsequently correct the earlier self-image and priority difficulties discussed. Despite the serious negative consequences associated with implementing heightened technology, with these proposed alterations, these technologies can offer a net benefit for diabetic patients.

## VI. CONCLUSION

While Type 1 diabetes is a burdensome disease, technology has improved the treatment regimen. It is not a miracle ‘fix-all’ solution, however, and current trends show that improvement is indeed necessary. I believe that progress in these areas is plausible and achievable. With increased effort into simplifying availability of diabetic technologies, I believe diabetics will be in a better position to enhance their physical and mental health if they do not need to worry as intensely over insurance involvement, reorders, doctor’s prescriptions, and more. Our sensitivity in the medical field can be improved, further allowing diabetics to push off any perceived pressures to measure up in comparison to fellow or hypothetical ideal diabetics. Overall, chronic illness can be a nonstop burden, but the technologies created and philosophical frameworks discussed can greatly improve care and reduce burdens of care.

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