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**Designing for Lived Experience:
A Suite of Tools for People with Type 1 Diabetes**

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**Designing for Lived Experience:
A Suite of Tools for People with Type 1 Diabetes**

by

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Report

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Dedication

This work is dedicated to Nicole Kinbarovsky, who not only made my studies possible, but enabled them to be positive, profitable, and passionate. Your love and concern for my wellbeing has made these years truly rewarding. Thank you so much, Nicole.

To my children, Una and Vivi, I send my thanks for your patience and love into the future. Reach for your intellectual and spiritual happiness.

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The work of two diabetes researchers was critical to my thinking in this thesis work: Heather Stuckey and David Morris. Their work on diabetes and narrative, and diabetes and temporality, respectively, allowed me to move from theory to action, and into the realm of product design. Without their example, it is unlikely I could have progressed so far, so fast.

Additionally, Diego Rojas assisted me in prototyping the work highlighted in this report. Without his help this project could not have been completed.

Abstract

Designing for Lived Experience: A Suite of Tools for People with Type 1 Diabetes

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The University of Texas at Austin, 2014

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Diabetes is a chronic, patient-managed illness. Type 1 diabetics must maintain near-constant awareness of their blood sugar levels and perform frequent medical interventions in order to remain alive and healthy. Research has shown that symptoms of poor treatment adherence manifest both physically and emotionally. While a great deal has been written about, and many products designed for, treatment of physiological symptoms and outcomes, far less has been written about, and even fewer products designed to address, the emotional experience of the type 1 diabetic. Yet the emotional effects of chronic illness have been well documented, including the effects of blood glucose variation on mood (Penckofer, 2012) and increased comorbid depression among diabetics (Anderson, 2001).

For my thesis project, I have created a connected system of physical and digital tools called the *t1D Suite* that addresses the unique emotional needs of people with diabetes, thereby bridging the gap between life-giving treatment and life-enriching experience.

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Introduction

Type 1 diabetes is a chronic, patient-managed illness. Type 1 diabetics must maintain near-constant awareness of their blood sugar levels and perform frequent medical interventions in order to remain alive and healthy. Research has shown that symptoms of poor treatment adherence manifest both physically and emotionally, which in turn have negative effects on treatment adherence and health, creating a vicious cycle of physical and emotional outcomes. While a great deal has been written about, and many products designed for, treatment of physiological symptoms and outcomes, far less has been written about, and even fewer products designed to address, the emotional experience of the type 1 diabetic. Yet the emotional effects of chronic illness have been well documented, including the effects of blood glucose variation on mood (Penckofer, 2012) and increased comorbid depression among diabetics (Anderson, 2001).

The DAWN and DAWN2 studies are the largest-ever efforts to understand the as-of-yet unmet needs of people with diabetes worldwide. Sponsored by Novo Nordisk, a Danish healthcare company, these studies established a strong correlation between people with diabetes' unmet emotional needs and adherence to treatment. 45% of the more than 15,000 respondents reported elevated levels of diabetes-specific emotional stress, while 14% could be characterized as having depression (Peyrot et al., 2005; Peyrot, et al., 2013). Elevated levels of stress and depression have been found to double or triple loss of adherence to treatment and increase healthcare costs by as much as 86% (Ciechanowski, et al., 2000; DiMatteo, et al., 2000).

Although the body of literature addressing the relationship between emotional state and adherence to treatment continues to grow, the healthcare product marketplace provides few options for managing the emotional aspects of chronic illness, and even

fewer that are specific to type 1 diabetes. As the healthcare industry moves towards a more patient-centered approach, and connected consumer technologies gain traction in the markets, the healthcare environment is ripe for innovation in its approach to patient-led, chronic illness treatment. Employing a cross-disciplinary approach to research and theory (including insights from neuroscience, sociology, psychotherapy, philosophy, rhetoric, and art), this report proposes a suite of simple-to-use, connected mobile and in-home tools to help type 1 diabetics monitor their emotional state as a means of improving their overall emotional well-being in the face of a chronic illness, which in turn can increase their ability to self-manage the physiological aspects of the disease, resulting in more positive health outcomes.

RESEARCH

In my thesis project, I sought to more deeply understand the relationship between treatment and emotion by adopting a perspective different from that often used by researchers and clinicians. Instead of investigating only the effects of emotion on adherence, I also examined the effects of adherence on the emotions and lived experiences of people with diabetes. This “reverse” perspective provided important insight into why people with diabetes sometimes resist treatment, despite being well of aware of the physical damage that can result. My theoretical and ethnographic research uncovered several meaningful and actionable insights: people with diabetes experience an unwelcome *disruption to their sense of freedom*, and *disruption of their life-narrative*, as a result of adhering to treatment.

Literature Review

In *Being and Time*, philosopher Marten Heidegger explores how humans relate to time. His theory regarding co-temporality sheds light on what I call the *provisional nature of diabetic living*, in which a continuous self-narration of blood glucose balancing prompts the diabetic to provide for (“provision”) his damaged body (Morris, 2008; Stone, 2010). Diabetics’ near-constant preoccupation with monitoring glucose levels and provisioning their bodies accordingly (with insulin or food) makes it difficult for them to experience what Heidegger terms ‘improvisational temporality’; or, put simply, freedom from the awareness of time. As philosopher David Morris suggests, ‘To be diabetic is to sometimes experience oneself as living a life not one’s own, since one’s life is not opened by one’s choices, but clocked by what must be biologically provided... it is the body itself that here is the enemy of freedom.’ (Morris, 2008). Morris considers this sensation

to be at the root of *diabetic rebellion*, in which treatment is rejected in hope of regaining a lost freedom. Considering the work of Heidegger's early theory in relation to the phenomenology of the diabetic, it becomes apparent that to counter the loss of freedom brought on by a life narrative interrupted by timekeeping, the diabetic could—and would almost have to—consciously construct an alternate, more productive narrative.

Diabetes researcher Heather Stuckey works on exactly this question, and investigates how creative expression can help people with diabetes construct positive narratives. Glucose swings, healthcare interventions, and continuous provisional timekeeping are all associated with negative emotions for most people with diabetes. Stuckey's work investigates how people with diabetes make meaning from these events and emotions. She connects expressive activities, such as amateur photography, to treatment, suggesting that, 'by focusing on diabetes as only 'numbers', rather than as an experience that affects individuals...on psychological, emotional, and spiritual levels, clinicians and people with diabetes are addressing only the medical experience of diabetes' (Stuckey, 2010).

In contrast to the clinical approach to diabetes treatment, therapist Michael White's research into narrative therapy seems to offer evidence of the efficacy of deliberate narrative building in promoting emotional healing and constructing a more positive life story (White, 1990). Similarly, cognitive scientist Robert McCauley's work suggests that religious and spiritual narratives might provide one useful model for diabetic narratives. McCauley argues that religion and spirituality are so compelling and long-lived because they describe events in precisely the narrative style humans most readily understand. If diabetics are understood to exist in *provisional temporality*, which requires what McCauley might call 'unnatural thinking' – clocking, calculating, and scientific reasoning—one way to change that narrative might be to frame those repeated

actions as religious or spiritual rituals, and to think of the artifacts that enable the clocking and calculating (the blood tester, the lancet, the syringe, and the insulin pump) as symbolic or fetishistic ritual objects that reveal profound truths by making visible and countable the invisible or ineffable.

The upshot of Morris's, Stuckey's, White's, and McCauley's work is that using creative expression as a means of constructing alternative narratives appears to be a useful method for reconciling diabetics and their diabetes. And in particular, McCauley's work suggests that there is an opportunity to rethink the forms and materials of clinical, impersonal medical devices so that they would have more symbolic and spiritual resonance for diabetics (Stuckey, 2010; White, 1990).

Phenomenological Research

PERSONAL EXPERIENCE

I have a fair amount of insight into diabetic lived experience as a result of 26 years of managing the emotional and physical aspects of my own type 1 diabetes. As of this writing, I have tested my blood sugar more than 66,400 times. My own experience with diabetes began during the winter break from elementary school in 1987. At the age of 11, I was inducted into a world of ritual testing, calculations, and dietary restriction. It was more than a metabolic change; it was what I call a *metaleptic break*. My narrative-driven life could not make sense of the change. Having been raised as a 'preacher's kid', I rested on what I knew—Western Christianity's notions of good and evil, right and wrong. Regardless of my parents' more nuanced clinical understanding of the illness, my young mind narrated the diagnosis, daily regimen, and glucose events as the result of either my own sin or the intent of an evil spirit. So began a decade of negative meaning-

making surrounding my illness. This poor narrative construction made treatment all the more difficult and onerous, and added to the already overwhelming cognitive load brought on by the endless measuring, calculating, and balancing of my blood sugar levels, leading to several extended episodes of rebellion against treatment.

CONVERSATIONS

I suspected I was not unique in finding the management and control of diabetes to be burdensome both physically and emotionally. I had conversations with type 1 diabetics via Skype to better understand how other diabetics think about their lived experience. I engaged in these conversations in order to ask specific questions that I had not found in my review of the available literature, or to ask questions within a specific context, namely within conversation rather than questionnaire, survey, or clinical setting. The questions were open-ended so as to allow the interviewees to describe their experience in narrative form and with terms of their own choosing. (For privacy's sake, the interviewees' names have been changed.)

The questions were as follows:

- How often do you think about your blood sugar?
- In general, what or how do you think about your diabetes?
- What is the best thing about your experience with diabetes?
- Do you experience specific emotions that go along with highs and lows?
- What do you do to help you live with your diabetes?

A young designer in his early 20s, "Zachary," who had been diagnosed in his college years, expressed the sentiment, "There are days when having diabetes is super

tough, and I feel like my body is fighting itself.” Similarly, “Lynn,” a mid-20s law student diagnosed at age 4, offered, “I think about [my blood sugar] very frequently; constantly throughout the day.” “John,” a mid-40s manager at a software firm, confided, “I’ve woken up with the paramedics trying to get me out of a low blood sugar attack, and you know, that’s just horrible. So I’m just always nervous about that going to bed.” Taken together, these statements demonstrate a few of the ways in which, according to Heidegger’s theory, diabetes’ complicated management routines and often difficult-to-achieve treatment goals may decrease the sensation of freedom.

In contrast, “Stewart,” a diabetes motivational speaker and mountain climber, suggested that, “Well-controlled diabetes has no symptoms, and we have the technology, if we adhere to it, to maintain that control to the point where diabetes does not have to negatively impact our lives.” Yet “Felicia,” an accomplished attorney and recent retiree, stated that, “Every piece of equipment I’ve ever had has been minimally useful.” Although the devices that have been developed over the last 60 years have improved glucose control, they do not address the emotional life of people with diabetes, but instead focus exclusively on the physical manifestations of the illness. While some people with diabetes, like Stewart, are able to make very effective use of the devices on the market, others, like Felicia, run into a surprising barrier – an incompatibility with the way people with diabetes think. What is not initially clear is the fact that Stewart has enormous overlap between his diabetic experience and his income and schedule. As the owner of diabetes non-profit, he makes his living motivating young people with diabetes and literally climbing mountains to draw attention and funding to research. He has managed to find a way to make controlling his diabetes an integral part of his source of income, but he is in the extreme minority. Felicia, Lynn, Zachary, and John are perhaps more typical in their struggle to integrate their disease management into their lived

experience, and as such find the devices and treatment techniques to run counter to their natural ways of thinking, as described previously by Robert McCauley.

DESIGN

My design work rests primarily on the theoretical rationale of constructionism. “Self-narrative” has been described as an individual’s effort to establish connections between life events in order to make them meaningful (Gergen, Cohler, Kohli, Bettelheim). Type 1 diabetics experience painful and traumatic events due to their illness, and over a period of time can suffer from poor narrative construction (Stuckey, 2010)(White, 1990). The negative narrative shapes responses to future events and predisposes people with diabetes to anxiously anticipate the next illness-related emergency.

In a technical sense, my design process has followed the Analysis-Synthesis Bridge model suggested by Dubberly, Everson, and Robinson. The Analysis-Synthesis Bridge model moves in a general order from research (‘what is’) to prototyping (‘what could be’), while frequently retreading previous steps as the work progresses and is clarified (Dubberly, et al, 2008). For the purpose of clarity in this written work, I am re-interpreting them as research: (1) Discover, and (2) Reframe; and design: (3) Envision, and (4) Create. The ‘discovery’ process has been discussed in the previous section covering research, while the subsequent steps will be loosely described in this section.

REFRAME

Following the research, and in keeping with the inverted perspective of treatment’s impact on lived experience, I focused my design process on three problem statements:

First, positive narrative building is difficult to achieve when facing comorbid depression, mood swings, and a host of other emotional difficulties associated with type 1

diabetes. I believe this problem is best addressed by countering the negative meaning-making occurring in diabetic experience through creative expression and self-reflection. Technology offers the possibility of expanding and extending both physical experience and creative expression in truly meaningful ways, if treated with consideration and care.

Second, diabetic treatment is notoriously difficult to maintain, yet technology has only addressed the scheduling of routine but not the emotional resistance to it. Current type 1 diabetes treatments require immediate, undesirable actions to achieve distant goals. I believe that incentivizing those immediate actions, such as blood testing, with immediate benefits, can lead to both short- and long-term increases in quality of physical and emotional health and happiness.

Third, type 1 diabetics rarely escape the ‘tyranny of numbers’ associated with numerous calculations and attention-sapping concern for blood glucose levels, but to my knowledge all existing digital and physical tools advocate an extension of numbers and calculations further into the diabetic consciousness. In fact, most tools also expand the volume of numbers to be considered by the diabetic at each interaction.



Illustration 1: A sampling of meters dating from the mid-1980s to present;
[http://upload.wikimedia.org/wikipedia/commons/3/38/Glucose_meters.j](http://upload.wikimedia.org/wikipedia/commons/3/38/Glucose_meters.jpg)
pg

ENVISION

From the research of Tillich, McCauley, Stuckey, White, Morris, and Gergen, a picture emerges of what an interactive self-therapy might look like for the temporally challenged, numbers-weary, emotionally overwhelmed diabetic: it would be a space in which symbolic language emerges from interaction between the diabetic and his diabetes, where glucose testing brings about an expression of the unified self, where glucose readings are in the shared environment rather than locked within the individual, and where over time the diabetic can begin to see herself as a whole being with unique understanding, emotions, and meaning.

My design goal is to bridge the gap between life-giving treatment and life-enriching experience. The reframing work done by reversing the traditional perspective suggests that the devices used to maintain control play a more significant role than previously assumed. To that end, I have created a connected system of physical and digital tools called the *t1D Suite* that addresses the unique emotional and temporal needs of diabetics.

Ioanna Patera, a religion, ritual, and material culture researcher, terms ritual objects ‘material supports’, suggesting that they “serve as identifiers of ritual attitudes” (Paterna, 2012). Devices for diabetic treatment are unique within their positions in the relationship between the diabetic and his disease. The glucose tester provides vital information for the diabetic to maintain glucose balance, yet requires blood in exchange. *Demand for such intimate bodily interaction is at the heart of the diabetic experience.* Paterna suggests that researchers believe that in the ancient world, “few vessels would be necessary for ritual and they would, most likely, have been made of metal.” Metal objects, being difficult and time-consuming to produce in the ancient world, stood in contrast to the ‘profane’ wood and pottery items. Carved animal bones and shells, due the

symbolic nature of their centrality to cultures, are often ritual and ceremonial objects (Illustration 2). Small, portable, ritual objects such as prayer beads blur the lines between sacred and profane. Made from more common materials, they may be used by laity to create sacred time in the midst of profane daily activities (Illustration 3). In the modern, post-industrial era, ‘profane’ objects are fabricated from plastics, metals, and silicon, while ‘sacred’ objects are frequently formed by hand using formerly traditional materials, such as wood, pottery, and particularly fine metals.

The poetics and aesthetics of religion and spirituality can be a useful way to imagine the routines and requirements of diabetic treatment. A distance between the individual and his body is felt throughout the life of the diabetic, and so the use of poetics in the form of aesthetics and symbolism give name and form to a complicated illness that seems to inhabit the blood. The scaffolds of religion and spirituality are found partly in ritual, which are of great importance when considering adherence to treatment. In religious studies scholar Catherine Bell’s view, ritual requires invariance, which is characterized by bodily discipline and enduring repetition. The careful choreography of diabetic testing and treatment require a great deal of bodily discipline and enduring repetition, similar to the monastic prayer and dietary control meant to shape emotion (Bell, 1999). The testing of one’s own blood can be considered a sacred interaction in that it reveals understanding which is of utmost importance to the diabetic and requires prescribed sets of performances. Blood is strongly associated with life itself in a majority of world cultures, and is a central component of many religious and secular rituals (Illustrations 4, 5). Concepts such as royal bloodlines and the antebellum ‘one drop rule’ illustrate the degree to which blood has been associated with identity and value. When a skill or passion is referred to as ‘in the blood’, the interwoven nature of an individual’s blood and body with individual identity is implicit. Blood testing is deeply intimate, even

if it becomes mundane and routine, as rituals often do. The entire set of diabetic rituals may be viewed with a greater degree of reverence through a more considered approach to the ritual objects used to ‘practice’ diabetes.



Illustration 2: Chavin Ceremonial Shell Trumpet, 400-200 B.C.E., is both utilitarian and symbolic;
http://cdn2.brooklynmuseum.org/images/opencollection/objects/size4/L52.1_transp5626.jpg



Illustration 3: Buddhist prayer beads are tactile and invite repetitive touch;
http://upload.wikimedia.org/wikipedia/commons/thumb/2/2e/Buddhist_prayer_beads_05.JPG/1280px-Buddhist_prayer_beads_05.JPG



Illustration 4: Blood and ritual have been interwoven for millennia; Olmec-style jadeite "bloodletting spoon", from Guerrero. 1500-300 BC;
http://commons.wikimedia.org/wiki/File:Olmec_bloodletting_spoon.jpg



Illustration 5: Modern Mayan bloodletting tool, Guatemala, Contemporary;
http://www.sfu.museum/cco_images/artifacts/Large/1998.001/1998001002A.jpg

CREATE

Reimagining the way people with diabetes understand blood testing is central to the design of *t1D Suite*. By treating the medical devices with the same degree of reverence that the diabetic must regard treatment, they demonstrate that they are more than technological methods of management; they become talisman and totem – emblematic of the process and persistence of life.

To help offset the provisional temporality described by David Morris, and provide scaffolding for the creative expression Heather Stuckey discusses, *t1D Suite* minimizes metrics-oriented thinking by using color, light, and sound to communicate glucose levels and emotions, keep time, and elicit creative and self-reflective activities. These design solutions work to minimize the labor of timekeeping and to encourage actions that promote diabetics' and their families' understanding of their emotional states within the private context of the home.

In order to provide a flexible framework for a wide variety diabetic experiences, the *t1D Suite* runs in two modes - passive and active (Illustration 6). The physical tools (tester, lamp, speaker) react to the routines and habits of the diabetic, springing to life when the blood is tested, and again when routine suggests retesting. They require only the test to activate; no further interaction is required of the user. The tester has been named 'Wayfinder', and the lamp/speaker 'Beacon', in order to draw out the navigational aspects of the tools, while nodding towards the more ethereal nature of the diabetic journey. The digital component of the *t1D Suite*, an iOS mobile application, not only serves as an archive of past glucose readings, but also provides creative expression outlets to aid in narrative building.

Glucose ranges are expressed on one hand in musical keys, which have been shown to have a high congruence with particular emotions in a wide variety of cultures

(Dissanayake, 2006; Tesoriero, et al, 2012; Goerlich, et al, 2011; Goethem, et al, 2011). For instance, the key of D# minor is perceived as ‘anxiety’ while D major expresses triumph (Bretherton, 2003). As a design and marketing industry-standard in color, Pantone follows popular color trends and reports on brand efficacy in terms of color use. For the purposes of communicating color range, Pantone offers useful guidelines on popular perceptions of color. On the other hand, colors are also utilized as they have some association with mood. It is important to mention that while colors are often associated with specific emotions anecdotally, controlled research has not borne out universal perceptions in the way popular culture – or marketing messaging – often suggests (O’Conner, 2010). Therefore, *t1D Suite* uses the Pantone Guide to Communicating Color (Eisman, 2000), but with the understanding that it rests on shifting cultural tides.

t1D Wayfinder

The Wayfinder is a fine Cocobolo wood glucose tester, hand crafted and carefully designed to invite interaction through sight, touch, and testing (Illustration 7). The wood darkens over time with use, and refers back to those sacred objects discussed previously, suggesting a longevity and tradition not found in any previous meter found on the market. A soft LED lamp glows from deep within the form, expressing blood sugar range while allowing for an intimate testing experience. The Bluetooth-enabled device uploads precise glucose readings to the iOS app, making it actionable in the case of ‘out-of-range’ readings.

t1D Suite Mobile Application (iOS app) with Suite Songs

The digital interface (iOS app) is active in that it requires some interaction to be most useful, but also allows for personal narrative building *without* an overly prescribed interface, such as drop down menus or predefined narratives (Illustration 8). The app helps to build positive narrative by encouraging personalized self-reflection and creative expression. The *t1D Suite* mobile application utilizes the data from *Wayfinder* as way to engage (and even collaborate with) diabetes in order to improve narrative construction. The built-in sequencer uses blood sugar readings as the basis for musical composition, so that low blood sugars, for instance, can become low blood sugar songs rather than just stressful events. Assigning the songs to the *Beacon* settings turns the composition into a song for all to hear and understand.

t1D Beacon

To externalize the disease, the *t1D Suite* communicates blood glucose readings into the home environment through color and sound emitted by the *t1D Beacon*, a wirelessly connected lamp and speaker (Illustration 9). The system reacts to glucose readings by activating the multicolor smart lamp and speaker. Like a monastic bell calling the community to supplicate, Beacon presents timing cues for medication and testing, and invites the family to collaborative care, which has been shown to improve adherence dramatically (Solowiejczyk, 2004). It is noteworthy that the Benedictine bell, indicating the transformation from profane to sacred time, was the precursor to the clock, an integral component of the diabetic process. Placed on top or in front of a sacred building or place, the bell projects outward, beckoning all to lay down profane pursuits to enter into a sacred temporality. Beacon, too, lives out ‘in front’ of the diabetic, externalizing the experience and including the family ‘community’ in the ritual.

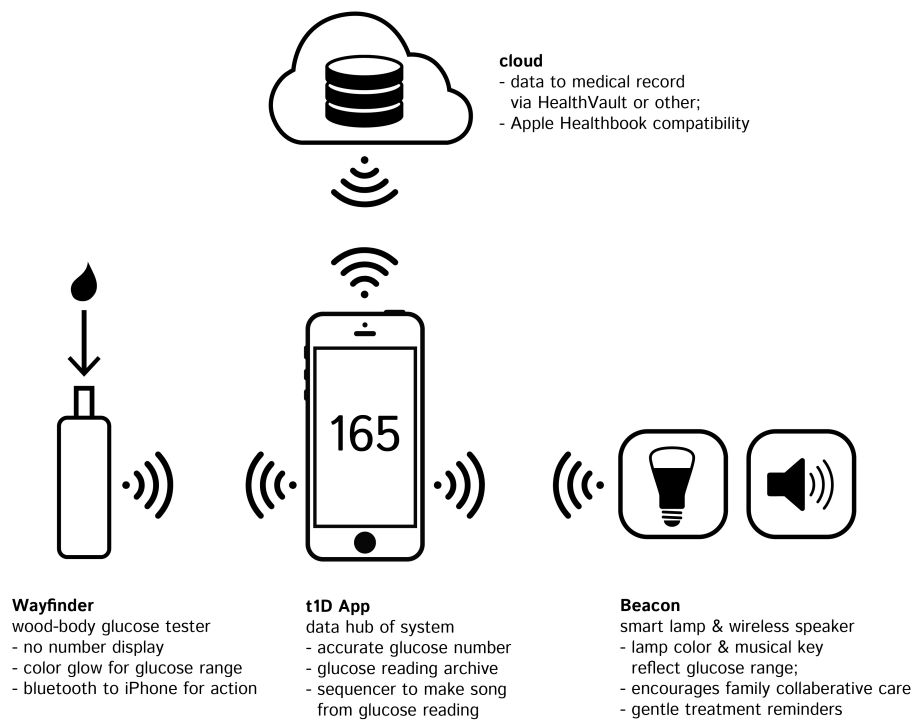


Illustration 6: The t1D Suite System Map



Illustration 7: The t1D Wayfinder blood glucose tester; Photograph by Nicole Kinbarovsky



Illustration 8: Suite Songs app for iOS; Photograph by Nicole Kinbarovsky



Illustration 9: The t1D Beacon connected smart lamp and speaker. Photograph by Sandy Carson.

Future Research

The future of consumer technology promises an ever-greater degree of connectivity, a proliferation of high quality embedded sensors, and home-based 3D printing. As Google Fiber moves into more cities around the world, enabling new sharing technologies and a more universal connectivity, communication between people and devices will grow exponentially. While the current state of continuous glucose monitoring systems (CGMS) are slow and vary in accuracy, new generations of sensors (e.g., Google's glucose-sensing contact lens) are likely to close the gap between themselves and meter-based testing, which is immediate and highly accurate. The t1D Suite is preparing to utilize wireless biosensor technologies to enable sensor-to-device communication, moving treatment even further toward intuitive, engaging interactions. Finally, in accordance with a future in which home 3D printers are commonplace, digital files for printing a personalized tester body have been designed for release to the public, and design plans have been laid for a glucose meter 'kit' including required electronic components. The possibility of people with diabetes building their own 'ritual devices' using almost any object or material is an exciting one.

Conclusion

The t1D suite of tools ultimately recognizes and engages several realities of the lived diabetic experience that have to date been largely ignored in the healthcare market: the emotional toll that daily adherence and physiological response takes, and the individual, intimate nature of self-care. Created using insights from many different fields (medical research, philosophy, religion, etc.), the t1D Suite invites interaction with one's diabetes that is more meaningful, more intimate, and more playful than traditional healthcare approaches.

But there is a larger story here. Interest in wearable sensing technology and health-related applications and devices is reaching fever pitch, contributing to an 'internet of things.' The 'quantified self' movement has become an attractive startup investment opportunity, and leaders in the field are proposing a 'personal dashboard' for everyone, assuming a deeper understanding of the self and opportunities for better choice-making will result.

But the industry can learn something from people with diabetes, who have been quantifying themselves for more than a generation; indeed, many type 1 diabetics have done so since childhood. The blood sugar readings and subsequent medication calculations that people with diabetes have viewed and used day after day, year after year, have been life saving, but given the option, most would never look at a daily or even weekly biometric again. Many people with diabetes feel this way because they discover a core truth about themselves over time – human beings are emotional creatures, and need to understand the world emotionally. The blood glucose metric is not used to build better versions of ourselves, it is used to reach a baseline of healthfulness – staying alive and active as long as possible in the face of a deadly disease.

People do not usually experience the world as a list of attributes or measurements; rather, we build a narrative to make our experience in it meaningful. A look at the many permutations of religions around the globe and across time point to one overarching truth about us – we crave narrative. The current obsession with metric readouts springs from a dubious source – we do it because we’ve made technology capable of it and have equated better health with better living. Certainly health is a key component of good living, but a ‘personal dashboard’ should not be created with only this single dimension in view; it should follow our lead. It should exist within our life narrative rather than interrupting it. This perspective – collaboration over nudging – has the possibility of doing more good for individuals than a colorful but attention-sapping metric display because it draws all the possibilities of the quantified self to us, rather than asking us to accept additional cognitive load in our already frenetic lives. The reality is, human beings do not simply persist through time, we *lead* our lives with a narrative, and it behooves designers of medical devices to acknowledge that truth in the design of products.

Bibliography

- AADE7™ - American Association of Diabetes Educators. (2014). *American Association of Diabetes Educators*. Retrieved January 29, 2014, from <http://www.diabeteseducator.org/ProfessionalResources/AADE7/#Tools> for healthcare professionals
- Adams, F. M., & Osgood, C. E. (1973). A Cross-Cultural Study of the Affective Meanings of Color. *Journal of Cross-Cultural Psychology*, 4(2), 135–156.
- Anderson, R. J., Freedland, K. E., Clouse, R. E., & Lustman, P. J. (2001). The Prevalence of Comorbid Depression in Adults With Diabetes A meta-analysis. *Diabetes Care*, 24(6), 1069–1078.
- Belasco, D., & Eisen, A. M. (2009). *Reinventing ritual: contemporary art and design for Jewish life*. Yale University Press.
- Bhattacharya, J. (2011). Music induced emotions: Some current issues and crossmodal comparisons. In *Music Education*. Hauppauge, NY: Nova Science Publishers, Inc.
- Bird, F. (1999). Review of *Ritual: Perspectives and Dimensions* by Catherine Bell. *Journal for the Scientific Study of Religion*, 38(4), 566–568.
- Breland, J. Y., Yeh, V. M., & Yu, J. (2013). Adherence to evidence-based guidelines among diabetes self-management apps. *Translational Behavioral Medicine*, 3(3), 277–286.
- Bretherton, D. (2003). In Search of Schubert's Doppelgänger. *The Musical Times*, 144(1884), 45–50.
- Burke, E. (1767). *A Philosophical Enquiry Into the Origin of Our Ideas of the Sublime and Beautiful*. J. Dodsley.
- Cameron, F., & Jones, T. (2010). Barriers to achieving targets, risks of hyperglycemia and hypoglycemia in children. *Endocrine Today*.
- Campbell, L. H. (2005). Spiritual Reflective Practice in Preservice Art Education. *Studies in Art Education*, 47(1), 51–69
- Carrico, K. (n.d.). Ritual. *Cultural Anthropology, Curated Collections*(4). Retrieved from http://www.culanth.org/curated_collections/4-ritual
- Ciechanowski PS, Katon WJ, & Russo JE. (2000). Depression and diabetes: Impact of depressive symptoms on adherence, function, and costs. *Archives of Internal Medicine*, 160(21), 3278–3285.
- Cohler, B. J. (1994). *Personal narrative and the life course* (Vol. 4). New York: Academic Press.

- Curtis, M., & Bharucha, J. (2010). The minor third communicates sadness in speech, mirroring its use in music. *Emotion*, 10(3), 335–348.
- Davis, J. E. (2000). *Identity and social change*. New Brunswick, N.J.: Transaction Publishers.
- Diabetes Facts. (2014). Text. Retrieved April 19, 2014, from <http://www.nlm.nih.gov/medlineplus/diabetes.html>
- Dienske, L. (1944). Beyond Words: On the Experience of the Ineffable. *Phenomenology + Pedagogy*, 3(1), 3 – 19.
- DiMatteo M, Lepper HS, & Croghan TW. (2000). Depression is a risk factor for noncompliance with medical treatment: Meta-analysis of the effects of anxiety and depression on patient adherence. *Archives of Internal Medicine*, 160(14), 2101–2107.
- Dissanayake, E. (2006). Ritual And Ritualization: Musical Means Of Conveying And Shaping Emotion In Humans And Other Animals. In *Music and manipulation: on the social uses and social control of music*. (pp. 31–56). Oxford and NY: Berghahn Books.
- Drew, S. E., Duncan, R. E., & Sawyer, S. M. (2010). Visual Storytelling: A Beneficial But Challenging Method for Health Research With Young People. *Qualitative Health Research*, 20(12), 1677–1688.
- Eisman, L. (2000). *Pantone Guide to Communicating With Color*. Grafix Press, LTD.
- Fuller, R. (2006). Wonder and the Religious Sensibility: A Study in Religion and Emotion. *The Journal of Religion*, 86(3), 364–384. doi:10.1086/503693
- Garrett, C. (2005). *Gut Feelings: Chronic Illness and the Search for Healing*. Rodopi.
- Gergen, K. (1991). *The Saturated Self: Dilemmas of Identity in Contemporary Life*. Basic Books.
- Gergen, K. J., & Gergen, M. M. (1983). Narratives of the Self. In *Studies on Social Identity*. NY: Praeger.
- Giddens, A. (1991). *Modernity and self-identity: self and society in the late modern age*. Stanford, Calif.: Stanford University Press.
- Goble, E. (2011). *The Experience of Encountering the Sublime*. Max van Manen. Retrieved from <http://www.phenomenologyonline.com/sources/textorium/goble-erika-the-experience-of-encountering-the-sublime/>
- Goerlich, K. S., Witteman, J., Aleman, A., & Martens, S. (2011). Hearing Feelings: Affective Categorization of Music and Speech in Alexithymia, an ERP Study. *PLoS ONE*, 6(5), e19501.

- Goethem, A. van, & Sloboda, J. (2011). The functions of music for affect regulation. *Musicae Scientiae*, 15(2), 208–228.
- Gordon, S. (n.d.). Diabetes Can Take a Toll on Your Emotions. *Consumer HealthDay*. Retrieved from <http://consumer.healthday.com/mental-health-information-25/anxiety-news-33/diabetes-can-take-a-toll-on-your-emotions-664847.html>
- Hanson, C. L., Guire, M. J. D., Schinkel, A. M., & Kolterman, O. G. (1995). Empirical Validation for a Family-Centered Model of Care. *Diabetes Care*, 18(10), 1347–1356.
- Houseman, M. (2011). Trying to Make a Difference with “Ritual Design.” *Reflexivity, Media, and Visuality*, 699–706.
- Ingarden, R. (1961). Aesthetic Experience and Aesthetic Object. *Philosophy and Phenomenological Research*, 21(3), 289.
- Ioanna, P. (2012). *Ritual Practice and Material Support: Objects in Ritual Theories*. Retrieved from <http://wp.chs.harvard.edu/chs-fellows/2012/11/30/ritual-practice-and-material-support-objects-in-ritual-theories/>
- Johnson, J. L., Bottorff, J. L., Browne, A. J., Grewal, S., Hilton, B. A., & Clarke, H. (2004). Othering and being othered in the context of health care services. *Health Communication*, 16(2), 255–271.
- Kallinen, K. (2005). Emotional ratings of music excerpts in the western art music repertoire and their self-organization in the Kohonen neural network. *Psychology of Music*, 33(4), 373–393.
- Kant, I. (1960). *Observations on the Feeling of the Beautiful and Sublime*. University of California Press.
- Kaya, N., & Epps, H. H. (2004). Relationship Between Color and Emotion: A Study Ofcollege Students. *College Student Journal*, 38(3), 396–405.
- Kaye, J., & Raghavan, S. (2002). Spirituality in Disability and Illness. *Journal of Religion and Health*, 41(3), 231–242.
- Kukkonen, K., & Klimek, S. (2011). *Metalepsis in popular culture*. Berlin, DE: De Gruyter.
- Machajdik, J., & Hanbury, A. (2010). Affective Image Classification using Features Inspired by Psychology and Art Theory. In *MM '10*. Firenze, Italy.
- Markowitz, J. T., & Laffel, L. M. B. (2012). Transitions in care: support group for young adults with Type 1 diabetes. *Diabetic Medicine: A Journal of the British Diabetic Association*, 29(4), 522–525.
- McAdams, D. (2008). Personal Narratives and the Life Story. In *Handbook of Personality: Theory and Research* (3rd ed., pp. 242–261). NY: Guildford Press.

- McCauley, R. N. (2011). *Why Religion is Natural and Science is Not*. Oxford University Press.
- McCauley, R. N., & Lawson, E. T. (2002). *Bringing Ritual to Mind: Psychological Foundations of Cultural Forms*. Cambridge University Press.
- McDonagh, D., Hekkert, P., Erp, J. van, & Gyi, D. (2004). *Design and Emotion*. CRC Press.
- Michaels, E. (2002). *Life's meaning: the unification of God, matter, man, mind, and society : a treatise on the science of religion*. Victoria, B.C.: Trafford.
- Morley, S. (2010). *The sublime*. London; Cambridge, Mass.: Whitechapel Gallery ; MIT Press.
- Morris, D., & Morris, D. (2008). Diabetes, Chronic Illness and the Bodily Roots of Ecstatic Temporality. *Human Studies: A Journal for Philosophy and the Social Sciences*, 31(4), 399–421.
- Morris, M. E., Kathawala, Q., Leen, T. K., Gorenstein, E. E., Guilak, F., Labhard, M., & Deleeuw, W. (2010). Mobile Therapy: Case Study Evaluations of a Cell Phone Application for Emotional Self-Awareness. *Journal of Medical Internet Research*, 12(2). doi:10.2196/jmir.1371
- Mueller, L. (1986). *Monet Refuses the Operation; from Second Language: Poems*. LSU Press.
- Munsell, A. H. (1912). A Pigment Color System and Notation. *The American Journal of Psychology*, 23(2), 236–244.
- Nicol, J. J. (2010). Body, time, space and relationship in the music listening experiences of women with chronic illness. *Psychology of Music*, 38(3), 351–367.
- Penckofer, S., Quinn, L., Byrn, M., Ferrans, C., Miller, M., & Strange, P. (2012). Does Glycemic Variability Impact Mood and Quality of Life? *Diabetes Technology & Therapeutics*, 14(4), 303–310.
- Peyrot, M., Burns, K. K., Davies, M., Forbes, A., Hermanns, N., Holt, R., ... Skovlund, S. E. (2013a). Diabetes Attitudes Wishes and Needs 2 (DAWN2): A multinational, multi-stakeholder study of psychosocial issues in diabetes and person-centred diabetes care. *Diabetes Research and Clinical Practice*, 99(2), 174–184.
- Peyrot, M., Rubin, R. R., Lauritzen, T., Skovlund, S. E., Snoek, F. J., Matthews, D. R., ... Kleinebreil, L. (2005). Resistance to Insulin Therapy Among Patients and Providers Results of the cross-national Diabetes Attitudes, Wishes, and Needs (DAWN) study. *Diabetes Care*, 28(11), 2673–2679.
- Radde-Antweiler, K. (2006). Rituals Online : Transferring and Designing Rituals. *Online – Heidelberg Journal of Religions on the Internet*, 02.1.

- Reynolds, F., & Prior, S. (2003). "A lifestyle coat-hanger": a phenomenological study of the meanings of artwork for women coping with chronic illness and disability. *Disability & Rehabilitation*, 25(14)
- Romanoff, B. D., & Thompson, B. E. (2006). Meaning Construction in Palliative Care: The Use of Narrative, Ritual, and the Expressive Arts. *American Journal of Hospice and Palliative Medicine*, 23(4), 309–316.
- Rowe, M. M., & Allen, R. G. (2004). Spirituality as a Means of Coping with Chronic Illness. *American Journal of Health Studies*, 19(1), 62–67.
- Shinkle, E. (2010). "Video Games and the Technological Sublime" (*The Art of the Sublime*) (No. Issue 14). Tate.
- Smolicki, J. (2009). *Liminal point: reclaiming the significance of ritual through design proposal for the restorative experience*. Institutionen för interdisciplinära studier, Stockholm.
- Snoek, F. J., Pouwer, F., Welch, G. W., & Polonsky, W. H. (2000). Diabetes-related emotional distress in Dutch and U.S. diabetic patients: cross-cultural validity of the problem areas in diabetes scale. *Diabetes Care*, 23(9), 1305–1309.
- Solowiejczyk, J. (2004). The Family Approach to Diabetes Management: Theory Into Practice Toward the Development of a New Paradigm. *Diabetes Spectrum*, 17(1), 31–36.
- Soltes, O. Z. (2005). *Our sacred signs: how Jewish, Christian, and Muslim art draw from the same source*. Cambridge, MA: Westview Press.
- Stone, D. (2010). Exploring Heidegger's Ecstatic Temporality in the Context of Embodied Breakdown. *Schutzian Research: A Yearbook of Worldly Phenomenology and Qualitative Social Science*
- Tesoriero, M., & Rickard, N. S. (2012). Music-enhanced recall: An effect of mood congruence, emotion arousal or emotion function? *Musicae Scientiae*, 16(3), 340–356. doi:10.1177/1029864912459046
- Dubberly, H.; Evenson, S.; Robinson, R. The Analysis-Synthesis Bridge Model. (n.d.). Retrieved from <http://www.dubberly.com/articles/interactions-the-analysis-synthesis-bridge-model.html>
- Volgsten, U. (2012). The roots of music: Emotional expression, dialogue and affect attunement in the psychogenesis of music. *Musicae Scientiae*.
- White, M. (1990). *Narrative means to therapeutic ends*. New York: Norton.
- Williams, S. J. (1996). The Vicissitudes of Embodiment Across the Chronic Illness Trajectory. *Body & Society*, 2(2), 23–47.
- Wirth, K. (2009). *Musically Sublime: Indeterminacy, Infinity, Irresolvability*. Fordham Univ Press.