sugar works
an artistic exploration of diabetes

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SUGAR WORKS: 
AN ARTISTIC EXPLORATION OF DIABETES

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ABSTRACT

My visual work articulates the complexity of chronic illness by exploring personal implications of medical treatment. I manipulate sugar in ways that reflect my own experiences as a diabetic. Using sugar allows me to situate social, emotional and sensory experiences within an organic material that changes over time. I use sugar in forms that are vulnerable to the environment and ultimately deteriorate. This fragility and slow-motion-loss embody the emotional consequences of treating diabetes and evoke common experiences of unpredictability and hyper-vigilance.

From this studio practice I designed an arts-based research study to teach sugar pulling to diabetic patients. This study supports participants as they develop the language and metaphors needed to articulate their social and emotional experiences. By emphasizing patient perspectives this study contributes to the understanding of patient compliance, self-care and diabetes support.

Both my visual work and this study leverage the material properties of sugar to enable meaning-making and increase visibility for the social and emotional aspects of living with diabetes. Through experiencing my work in these two forms, I hope viewers will find a neutral space to contemplate the contradiction and uncertainty that often emerges alongside chronic illness.
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Art-making allows individuals to simultaneously discover relationships between concrete experience and abstract thinking. Because of this artistic inquiry is highly accessible to individuals and enables practitioners to engage diverse audiences, especially those whose narratives are underrepresented. Artists as primary agents of art-making have an ethical obligation to consider the applications and implications of their visual research. Why should this art be made? Who should participate? What good can emerge? Who will be impacted? How might this work challenge, transform, provoke, agitate, unsettle?

I experiment with visual processes in order to discover powerful metaphors that can be applied to social contexts and challenge inequitable power structures. My work with sugar investigates the social and emotional experiences of having diabetes in order to better understand the complexity of self-management and to re-distribute research attention to often missing patient perspectives. Through intentional processes, materials and forms, I have been able to contemplate my own diabetes diagnosis. Using sugar allows me to situate social, emotional and sensory experiences within an organic material that changes over time. I use traditional baking and candy-making techniques to transform granulated sugar into forms that are vulnerable to the environment and ultimately deteriorate. This fragility and slow-motion-loss embody the emotional consequences of treating diabetes and evoke common experiences of unpredictability and hyper-vigilance.

To understand the wider social value of my work, I have designed an arts-based research study that teaches traditional sugar pulling to other diabetics. Participants discuss how sugar pulling can be used as a metaphor for diabetic experiences and to better articulate complications with self-management. By focusing on patient perspectives, this study attempts to resolve a current research imbalance that emphasizes positivist paradigms and scientific narratives. My study provides an opportunity for individuals with diabetes to interact as peers and to contribute to the research narratives that impact treatment and support. The study asks: What experiences/meanings are had, shared and made by using traditional sugar pulling practices as a metaphor for managing diabetes? Through this ongoing study, I hope to demonstrate the value of using personal experience to better understand the impacts of chronic illness and to consider how art might be used to support diabetic patients.
BACKGROUND

Diabetes is a chronic illness that impacts individuals physically, emotionally and socially. Individuals develop diabetes when they are unable to make or adequately use insulin. Without insulin the body cannot convert sugar into energy. This leads sugar in the blood (glucose) to continually rise, which can cause health problems like nerve damage, vision problems, stroke, heart disease and kidney damage. Untreated, severe high blood glucose can lead to coma or death.

Successful management of blood glucose involves adopting a complex regimen that can include oral medication, insulin injections, diet and exercise implemented by the patient on a daily basis. Resistance to fully adopting a provider-designed regimen is common in diabetes as with many chronic illnesses; however, adherence to treatment can be difficult to measure. One literature review surveyed 10 studies measuring patient adherence to basal insulin regimens in Type 2 populations. Reviewers found that adherence rates range anywhere from 30% to 86%. This wide-range reflects the complexity of factors impacting adherence and reveal difficulties in generalizing rates. Research from the World Health Organization estimates that, in general, only 50% of chronically ill patients in developed countries comply with long-term therapies. Another study considered adherence rates from 1990’s – 2000’s and found that despite extensive quantitative research, adherence rates did not improve. The variance between studies reveals the difficulties in generalizing rates. Research from the World Health Organization estimates that, in general, only 50% of chronically ill patients in developed countries comply with long-term therapies. Another study considered adherence rates from 1990’s – 2000’s and found that despite extensive quantitative research, adherence rates did not improve. The variance between studies reveals the

1 Ironside et al., 2003, pg 180
2 Nall, 2018
3 Nefs et al. 2012
4 Guerci, 2018
5 World Health Organization, 2003
6 Ingadottir & Halldorsdottir, 2008
limitations of approaching adherence strictly through a medical perspective and implies a need for more qualitative research to help understand subjective factors present in the social and emotional experiences of diabetic patients.\textsuperscript{7}

In the past decade approaches to diabetes care and research have begun to expand to include not only medical perspectives, but also behavioral, social, and patient-centered perspectives. Researchers have documented the success of this expansion and recommended continued innovation in management and prevention to better reflect the impact of sociocultural and individual differences.\textsuperscript{8} This shift is supported in growing research into the social and emotional factors that contribute to non-compliance, as patients seek ways to preserve quality of life and find strategies that better suit their values, lifestyles and priorities.\textsuperscript{9}

After interviewing 11 diabetic patients who had experienced either serious compliance or noncompliance throughout years of treatment, Ingadottir and Halldorsdottir found that “knowing oneself and respecting the disease without letting it dominate one’s life is the key for successfully integrating what constitutes quality of life and a modified treatment regimen”.\textsuperscript{10} Framing treatment in this way requires new attention to the social and emotional aspects of diabetes. Approaching care from multiple disciplines introduces values and perspectives not inherently tied to medical practice. Art, for example, encourages appreciation of cultural, social and emotional content while also valuing subjective and individual experience.

In addition to providing a framework for considering subjectivity, emotional and social experience, art offers discipline-specific research methods that could support an interdisciplinary approach to diabetes. For example, arts-based research (ABR) methods have been shown to be an effective way to explore emotional and social experiences. Through art-making participants are able to generate, understand and express knowledge simultaneously.\textsuperscript{11} By using art-making as a metaphor, participants are able to put concrete words and images to phenomena that are more elusive and emotional. In this way participants visibly capture invisible experiences. ABR also offers the opportunity for a collaborative construction of knowledge and for participants to gain visibility for their perspectives.\textsuperscript{12} Outcomes like these can create new and valuable knowledge for diabetes research.

\begin{itemize}
\item \textsuperscript{7} Stuckey, 2009
\item \textsuperscript{8} Stetson et al., 2017
\item \textsuperscript{9} Ingadottir & Halldorsdottir, 2008, pg 608
\item \textsuperscript{10} Ingadottir & Halldorsdottir, 2008
\item \textsuperscript{11} Leavy, 2017, 196
\item \textsuperscript{12} Frey & Cross, 2011, 68
\end{itemize}
My thesis work marries ABR methodology with a studio-based approach to visual research. Each practice informs and enriches the other by changing the shape of analysis, critique, and presentation. I emphasize this symbiotic relationship through my exhibition design which includes both visual artwork and a text-based presentation of my ABR study. I want this visual synthesis to encourage viewers to try out new analytical and experiential approaches to engaging with the work. To consider the validity of my studio-based visual research, I employ types of criteria used in ABR. Rather than judge artworks solely by their historical, aesthetic or philosophical content, I consider how well an artwork taps into experiential knowledge and evokes emotional understandings. Work that resonates with an individual’s emotional and experiential knowledge can be applied to social situations to deepen one’s knowledge of self, support collaboration, access wide audiences, prompt social reflection and embrace multiple ways of knowing.\textsuperscript{13}

As an artist I am committed to considering the ethical implications of my work. ABR provides a framework to judge how well a work reflects experiential knowledge and emotions.\textsuperscript{14} To determine this requires me to engage audiences more directly and instigates additional critical and ethical questions like, why should I make this art? Who should participate? How can I apply this art to a greater good? By teaching other diabetics the sugar pulling process used in my studio work, I am able to record how well it reflects their own experiences.

Initial results from this ongoing study have helped to confirm the validity of my visual research and demonstrate the value of using art to support diabetic patients socially and emotionally.

\begin{flushright}
\textit{Exacting, 2019}  
Sugar, wire, metal  
Viewers watch as sugar falls through the net.
\end{flushright}

\textsuperscript{13} Leavy, 2017  
\textsuperscript{14} Leavy, 2017
UNCERTAIN FORM

My first exploration with sugar resulted in the piece, Uncertain Form. In this artwork, I suspend cast-sugar vessels above sculpted paper. After heating a mixture of sugar, corn syrup and water to 295°F, I pour the molten sugar into silicone molds. Once cool, the hardened sugar appears glass-like, taking the geometric shape of the mold. These vessels are particularly vulnerable to the environment because the hygroscopic particles attract water from the atmosphere. When this happens, the vessels appear to melt. To accelerate the melting process, I fill each vessel with ink. The ink dissolves the sugar from the inside, eventually weakening it enough to form cracks and holes. Ink then drips, spills, splatters onto the paper below taking unpredictable paths.

The unpredictable nature of Uncertain Form characterizes the relationship between insulin and the body. While science can explain the effect that ink has on sugar, just as it can explain the effect insulin has on the body, constant variables make accurate predictions difficult. The cast-sugar vessels, for example, change according to the environment. Different levels of humidity and heat begin to dissolve the sugar even before ink is added. Vessel thickness and placement
of the wire around each piece also impact where or when a crack forms. Even after a vessel begins to leak, the speed and duration is unpredictable. Insulin responds in a similar way. While patients may be prescribed a certain dosage, changes in the body and even outside the body can affect what happens. Insulin absorption can be affected by exercise, location of injection site, blood flow and exposure to hot or cold temperatures\textsuperscript{1} while stress, fluctuating hormones and immune response can directly impact blood glucose.\textsuperscript{2} This creates a difficult equation for patients trying to maintain a target range of blood glucose levels.

Viewing \textit{Uncertain Form} can also feel similar to monitoring blood glucose. Once ink is added to a vessel, viewers must wait to see what happens. This suspense mirrors that after injecting insulin. Both insulin and carbohydrates take time to absorb, making it impossible to immediately see if a dosage is correct. Instead, diabetic patients wait about 2 hours after eating to determine how closely the insulin absorption matched the carbohydrate intake. Waiting requires patience and attention. Diabetic patients might be anxious, especially if previous dosages were incorrect or they may be hopeful that a dose will work out. Viewers of \textit{Uncertain Form} might also feel

\begin{thebibliography}{2}
\bibitem{1} Donner, T, 2015
\bibitem{2} Mayo Clinic, 2018b
\end{thebibliography}
anxious or hopeful, because they are unable to predict where ink will splatter or how quickly it will spill. I use paper to document the unpredictable marks created as ink spills from newly made cracks and holes. Previous unknowns become a permanent record like data collected by blood glucose monitors. Even as new marks accumulate viewers can reflect on the accuracy or inaccuracy of their predictions, just as patients use previous blood glucose data to make sense of insulin absorption.

Once the ink seeps from each vessel, water in the air continues to degrade the sugar until nothing remains. Rapid dripping becomes slow-moving drops of syrup, then silence. This process may take days or weeks, depending on humidity levels and the thickness of each emptied vessel. This slow-motion-loss typifies chronic illness. Diabetic patients may experience damage to their nerves, kidneys, retinas, joints, bones, teeth, gums and cardiovascular system after years of high blood glucose levels.\(^3\) Loss of these functions is unpredictable and slow, creating nuanced emotions that may be difficult for patients to articulate or understand. Uncertain Form gives space to experience and contemplate this kind of emotional ambiguity, prompting both delight and apprehension, curiosity and hesitation. In this way Uncertain Form encourages viewers to make peace with contradiction and cope with the unknown.
FOILED

Nets are used in various settings to catch, connect, protect, hold, support, cushion and separate. In Foiled I create a net that subverts typical netting functions as a way to imagine the relationship between patients and medical practice. While the purpose of medicine appears similar to that of a net – supporting and protecting the body when faced with disease and injury - medicine can also be a source of vulnerability and conflict. Side-effects, limitations and complications frequently coincide with treatment. This tension between healing and hurting becomes an intimate condition for patients who might face internal conflict or difficult decisions during treatment. Acknowledging the fragility and consequence of medical treatment in the body also welcomes similar investigation of personal and emotional experiences. Drawing inspiration from my own experiences with synthetic insulin, Foiled invites viewers to consider the intimate, fragile, and highly personal side of medical care.

Foiled, 2019
Sugar, wire
In *Foiled* fragility is created through the combination of sugar and wire. After heating sugar to 290°F, I pour it over the net. Most of the liquid form seeps through the net, beading around random sections of metal. Once cooled the flexibility and movement of the net poses a risk to the brittle sugar. Any movement, even subtle ones, knock sugar loose from its precarious position. With larger holes the net is unable to catch, hold or prevent sugar from falling away. While flexibility and movement typically provide strength to nets by conforming around objects, in *Foiled*, they create tension and fragility particularly for the hardened sugar.

This tension illustrates the relationship between the rigidity of synthetic insulin in the midst of ever-changing conditions of the body and reflects its emotional consequences. With a functioning pancreatic system, the body can respond immediately to small changes in blood glucose, keeping within a narrow range. For diabetics first blood glucose changes need to be measured by a meter then adjusted with synthetic insulin that takes time to absorb. Once injected synthetic insulin cannot be stopped or adapted. It is stiff and rigid, like the hardened sugar on *Foiled*. To regulate blood sugar, diabetic patients either predict what might happen in the future or react to what has already happened in the past. For healthy people insulin
and blood sugar have a harmonious and immediate relationship. With diabetics this relationship becomes imprecise and vulnerable. Any variation in body, habits or environment make regulating blood glucose more difficult.

The physical vulnerability between insulin and the body translates to emotional vulnerability. While diabetic patients may comply with prescribed dosages and regimens, external factors can push blood glucose outside the desired range causing patients to react emotionally. Stress, anxiety, shame, guilt, frustration, despair, anger can all coincide with undesired outcomes, linking the fragility of medical treatment to personal and emotional fragility. Successful blood glucose management requires patients to act independently of these emotions and to persevere through challenges.

Learning to persevere through challenges was essential to creating the net in Foiled. To create this I apply traditional net-making techniques to a fine gauge wire. The thinness of wire makes it vulnerable to the constant pulling, looping, tightening and often breaks under pressure. When I first began net making, I reacted strongly whenever the wire broke – with surprise, frustration, irritation, even anger. Like high or low blood glucose results, this breaking required me to persevere, adjust and mend. With more experience, I began to expect occasional breaking and learned easier ways to mend a broken strand. Similarly, as I have become more experienced with self-management of blood glucose, unexpected high or low numbers cause less extreme emotional responses.
Sugar poses a contradiction for insulin dependent diabetics. When too much sugar accumulates in the blood it can cause a health risk. At other times it can be the very thing that keeps patients alive. Without a pancreas to regulate insulin, the body cannot stop synthetic insulin from working even after blood glucose dips below a safe range. To bring blood glucose back up diabetic patients must consume something sugary.1 Because of this, patients might associate both negative and positive feelings towards sugar.

*Unsettled* embodies this contradiction. Using a traditional cotton candy making technique, I pull sugar into fine strands. To achieve this, I heat sugar to 270° F and pour it into a silicone mold. Once it cools to about 120°-90° F, I shape the warmed, malleable sugar into a single ring. Next, I cover the ring in cornstarch which forms a thin barrier around the sugar. I twist the ring into two loops then fold it into a doubled ring and repeat. The twisting, doubling, pulling process

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1. American Diabetes Association, 2019
is sometimes easy, sometimes difficult. In the beginning, the single ring responds to every subtle change. Its own weight further weakens any thinness created as hands squeeze and lengthen the loop. While uniformity protects against this kind of weakening, it is almost impossible to achieve because it requires synchronized movements. To overcome the unpredictability of the material, I rely on my own judgement, muscle memory and coordination. As I fold the sugar into more loops, uniformity decreases and suddenly the larger or more vulnerable pieces stand out or fall away from the rest of the group.

Learning this synchronized set of movements required time, practice and attention. For newly diagnosed diabetics, it can be particularly difficult to find the right balance between insulin and carbohydrates, especially when variables like exercise, diet and stress can impact their effects. With sensitivity to subtle changes and close analysis of data, patients may develop an implicit understanding of interacting elements. This subtle kind of attention matches that of pulling sugar. Acquiring the skills to be successful takes time and can be frustrating for patients who know the importance of maintaining target blood glucose levels but cannot instantaneously succeed.

As the sugar thins, continued pulling eventually breaks the loop into thousands of individual strands. I hang these strands over a ring and, immediately, the sugar responds to gravity. The whole group stretches towards the ground, until single strands break loose. Lighter than the group as a whole, single strands catch on surrounding pieces and appear to crawl in slow-motion down the bunch before falling to the ground. Visually Unsettled depicts emotions experienced by many diabetic patients. This can include the feeling of falling apart, slow-motion loss, fragility and recognition of eventual death.

The sensory experience of pulling sugar differs from the visual impact of Unsettled as an artwork. For example, while pulling sugar I learned to ignore the single strands and focus on the whole. If I became too concerned with an individual strand, everything else began to fall apart. Learning to look at the whole is vital for blood glucose management. It is
easy to react strongly to one high glucose reading rather than look at the comprehensive set of data. This can lead to over-correcting or other responses that complicate management. More than the other sugar processes I use, pulling sugar resonates with many experiences in self-management. Recognizing the metaphoric value of sugar pulling led me to investigate its value within a larger social context.
ARTS-BASED RESEARCH STUDY

Creating artwork in a studio has many benefits. Studio practice has little risk and therefore encourages experimentation and creativity; however, work also tends to specifically reflect an artist’s individual and personal views of the world. For me this limitation can be addressed by finding relevant ways to apply the work with others and to document the meanings created. ABR provides a critical methodology to responsibly apply artwork with an audience and extend the value of studio practice. Like other research, ABR has the potential to leverage the perspectives of those without power as a way to challenge oppressive structures and policies1 and to legitimize more voices in the cultural production of knowledge and meaning. As an artist I am committed to including voices other than my own and creating new opportunities for others to produce knowledge.

These convictions played an essential role in developing my ABR study as an extension of my sugar practice beyond my personal studio. The purpose of this study is to document the social and emotional experiences that contribute to blood glucose management and have implications for care. Participants take part in one 2-hour workshop where they learn to hand-pull sugar. Afterwards we discuss how sugar pulling can be used as a metaphor to describe experiences with managing diabetes. This study seeks to explore how participation might encourage articulation of social and emotional experiences within a healthcare context. By introducing the discipline-specific values of visual art, this study emphasizes ambiguity, creativity, and personal experience while also supporting growing interest in interdisciplinary approaches to diabetes care.

This study does not intend to provide generalizable data, but to provide insight into participant experiences. To be eligible for this study, participants must be over 18 and have diabetes. All participants are self-selected through recruitment materials approved by Indiana University’s Institutional Review Board. Currently, one participant has fully completed the study and recruitment efforts are ongoing.

1 Mertens, 2014, pg 32
During the workshop qualitative data is collected through written surveys, recorded interviews and video. Questions include: What were some of the physical/sensory experiences in this process that felt familiar or interesting to you as a diabetic? How did this relate to your past experience? How can we think of sugar pulling as a metaphor for diabetes? What was meaningful about your experience today?

Analysis of data from the first participant suggests the following. Emotions are difficult to separate from diabetes management. During self-care unwanted emotions like fear, anxiety, shame and panic can arise and impact decision-making. Patients show a need for tools that can help moderate the emotional experiences that coincide with testing blood sugar or teach patients to view glucose readings objectively. Language around blood sugar “control” negatively impacts self-care because it contributes to more emotional responses, like panic, anxiety, fear and frustration. This sugar pulling practice is helpful because it allows patients to dissociate from unwanted emotions and to think about their experiences in a neutral way.
I use sugar as a metaphor to reflect on the ways diabetes impacts my daily life. My sugar practice creates an invaluably neutral space to contemplate the emotional ups and downs that come with monitoring blood glucose levels. This reflects a similar experience of one study participant. When asked to describe the value of participating in the workshop, she noted, “It is important to come to terms with the emotional toll of diabetes and address it. It’s hard to normalize for yourself unless you confront the emotional burden first so you can move on from it rationally and with a level head.” Through continued work with sugar and this ongoing ABR study, I hope to better document the personal, emotional, and social needs diabetic patients experience while managing blood glucose.

Although this ABR study is ongoing, preliminary findings suggest that diabetic patients may experience emotions during self-care that can impact decision-making. These findings reveal the impact of personal experience and confirm the value of taking an interdisciplinary approach to diabetes. Further research should be done to understand how this impacts adherence to diabetes regimens and to develop tools to moderate unwanted emotions during self-care.

With a wider audience the results of my work with sugar can be used to help remove stigma surrounding diabetes, educate individuals and increase empathy for the challenges diabetics face. A 2017 report by the Center for Disease Control shows that over 100 million Americans are living with diabetes or pre-diabetes. This means that most people will live or work alongside someone with diabetes. Methods for educating individuals and improving understanding will be essential to creating an informed and empathetic public. Sugar pulling creates concrete and experiential learning opportunities for educating those who do not have diabetes.

Study participant places pulled sugar on ring.
Art allows individuals to make meaning that embraces emotional ambiguity and contradiction. I leverage this quality in both my visual artworks and the methods of my ABR study. My work develops an intimate approach to diabetes and provides an important supplement to existing quantitative data. By using qualitative methods my ABR study begins to contextualize why some patients struggle to manage blood glucose. Through art individuals can simultaneously feel or know opposing things. This makes my work uniquely capable of reflecting the multi-faceted, constantly changing, highly personal and sometimes contradictory experiences that impact diabetic self-care.

My thesis exhibition fully adopts this oppositional quality of visual art and ABR to allow viewers to contemplate, discover, empathize and engage. Because my artwork changes over time, viewers can actively watch and wait in anticipation. The dripping sugar activates multiple senses including sight, sound and smell, inviting viewers to develop an experiential understanding of emotional ambiguity and uncertainty surrounding diabetes. During the opening reception, some viewers were so fascinated by my artworks that they knelt on the ground, bent over, attempted to touch and even taste the active sugar. Physically involving viewers shortens the conceptual distance between their own personal knowledge and the ideas put forward in my work.

Sensory experience of unpredictability and emotional ambiguity can deepen one’s knowledge of complex phenomena beyond diabetes. These can be more widely applied to investigating human experience and considering the impact of time on organic matter. Other concepts, like slow-motion-loss and change-over-time can also describe broader human experience. In this way, my artwork provokes contemplation of both universal and uniquely personal experiences. By bridging the universal and singular, I seek to enhance empathy and strengthen embodied knowledge in my viewers.
REFERENCES


