Visualizing the Emotional Impact of Type 1 Diabetes Through Art

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VISUALIZING THE EMOTIONAL IMPACT OF TYPE 1 DIABETES THROUGH ART

by

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A Senior Project in Partial Fulfillment of the Requirements of the Honors Program
ST. CATHERINE UNIVERSITY
March 17, 2014

Acknowledgments
I’d like to thank from the bottom of my heart all of the people that let me into their lives through the interviews conducted during the duration of this project. To my committee, my sincerest thanks for helping me produce a body of work that I am proud of.

Thank you to Todd Deutsch, my project advisor, who kept me centered throughout this entire process and saw it through to the end. Thank you to my committee member Patricia Olson for always being flexible and offering a professional opinion from the world of painting. Thank you to Anna Engelhart for the medical insights and constant encouragement. Lastly, thank you to Tamsie Ringler who always challenged me to push my art further. I could not have asked for a better committee to help me through this project.

Visualizing the Emotional Impact of Type 1 Diabetes Through Art
Injury and disability have been subjects of investigation by artists for centuries through both universal and personal depictions. Art has the potential to portray experiences as well as both physical and emotional struggles. The overall project, “Visualizing the Emotional Impact of Type 1 Diabetes through Art”, focuses on the creation of art based on my own experience and the experiences of others directly affected by type 1 diabetes. To make this project resonate with those unfamiliar with diabetes, it is important to educate my audience on essential pieces of information while simultaneously providing a lens to understanding my inspirations.

Learning about Diabetes is proving to be a lifelong endeavor for me and many others that have been diagnosed with type 1. As with all chronic illnesses, people handle their care and initial diagnosis differently. I conducted interviews to gain a better understanding of the wide range of reactions and coping skills of type 1 diabetics of varying ages and backgrounds. I asked them a total of 20 questions that led me as the interviewer from their beginnings as diabetics, through their lives so far with the disease. In addition to the interviews of the diabetics themselves, I also wanted to know how caretakers responded to the diagnosis of their child. Within the paper, those interviewed will be identified only with the number that describes chronologically when they were interviewed, with “Interviewee 1” being the first diabetic person to respond to the questions and “Interviewee A” being the first non-diabetic parent to respond. The diabetic interviews will be marked 1 through 24 and the parent interviews will be marked with letters A through I. It also is important to note that when the term “diabetes” is used in this paper, it will always be referring to type 1 diabetes.
What is Diabetes?

There are several types of diabetes. The type of diabetes that I will focus on in this paper is type 1 diabetes. When I was diagnosed with type 1 diabetes in 1999 it was called Juvenile Diabetes due to the rate it appeared in children. Now the term “Juvenile Diabetes” is considered to be obsolete, as cases of adults developing this type of diabetes well into their 20s and later have been reported. Half of all diagnosed cases of type 1 diabetes occur in people under the age of 20, however, making it an increasingly common chronic illness developed by children (Gower, 11).

In 1889, it was discovered that diabetics had malfunctioning pancreases, a “large fleshy organ under the stomach that produces many of the digestive enzymes” (Matthews, 1). The pancreas serves several roles within the body. The roles that are disrupted with the onset of diabetes are the production of glucagon and the secretion of insulin.

Before the discovery of insulin in 1921, most afflicted children died from the disease. This changed in 1922, when insulin began being produced (or rather, extracted and sold) on a large scale. Treatment before then was nothing but a dietary adjustment that could only keep someone alive for a few years after the diagnosis (Feudtner, 172). According to Dr. Elliot Josilin, a pioneer in the treatment of diabetes in the 1920s who wrote what is considered to be the first handbook for diabetics, “there has never been anything discovered as valuable for the diabetic as insulin” (Feudtner, 174). He was a firm believer that with insulin, a patient could take charge of their own disease instead of relying so heavily on doctors.

A diabetic patient can work with his or her doctor to figure out good levels of insulin to convert sugar into food for cells and energy. Glucagon is a hormone that uses glycogen in the liver to raise the blood sugar by reconverting the stored glycogen to glucose. Insulin deficiencies
and unregulated glucose levels in the blood are the indicators of diabetes. Glucose is broken down in the body to provide energy and growth. Glucose, also referred to as blood sugar, is converted from carbohydrates, which are found in almost everything edible (Gower, 10). With type 1 diabetes, “...the beta cells of the pancreas are destroyed in an autoimmune attack, and the body can no longer make insulin. This destructive process occurs over many months or years,” meaning that the hormone needed to work with the glucose is in short supply, if supplied at all (Touchette, 15). Due to the long process of beta cell destruction, it is possible for months or years to go by without initial symptoms of diabetes occurring; making it difficult to pinpoint exactly when the cells were originally attacked. This, however, also makes it possible to diagnose and intervene with treatment to manage long term progression of the disease at certain stages.

Even a diabetic body has glucose in it; the problem arises when the glucose is prevented from entering the cells and being converted into energy. Insulin is essentially the “key” that unlocks the cells to allow the glucose in. When a pancreas produces less insulin than is needed, or in many cases none at all, basic functions become extremely difficult for the body. Type 1 diabetes is less commonly referred to as insulin-dependent diabetes due to the essential use of needle-delivered artificial insulin.

The importance of genetic susceptibility has been demonstrated in many research studies. When a person has a family history of diabetes, especially if one or both parents are diabetic, her/his chances of being diagnosed themselves herself/himself increase. When neither parent is diabetic, there is a 1 in 300 chance of their child developing type 1 diabetes. If either parent was diagnosed before the age of 11, the risk of having diabetic children when set against standard statistics and rates, is doubled. The rate of having a diabetic child is slightly higher when the
father is diabetic (a 1 in 17 chance if the father was diagnosed after age 11) than the rate of having a diabetic child with a diabetic mother (a 1 in 100 chance if the mother is older than 25, and was diagnosed herself before age 11) (Gower, 12). Due to the statistics, several of the interviewed diabetics expressed concern over the potential of having a diabetic child. None of the parents of diabetics were themselves diabetic, however.

There is still an incredible amount of speculation as to what causes type 1 diabetes. Simply stated, the disease is an autoimmune response in which beta cells within the body are attacked as if they were “...foreign invaders” (Touchette,13). The current discussion of debate in type 1 diabetes is around what causes the initial autoimmune response. Many researchers have determined that both genetic and environmental influences lead to the autoimmune destruction of beta cells.

**What Type 1 Diabetes Isn’t**

Type 1 diabetes is commonly mistaken for type 2 by those who are not educated about either condition. The most frustrating part of the lack of understanding is that many non-diabetics make it their mission to tell those diagnosed all about their illness. The use of “diabetes” as an umbrella term for multiple variations of pancreatic malfunction is technically incorrect, as there are several different kinds.

When asked in the interviews, “What do you believe all people should be aware of when it comes to diabetes?” the majority of the diabetics interviewed stated that they found it “insulting” when people, and even the media, treated type 1 and type 2 as interchangeable. Though all types of diabetes raise the risk of complications, they are not intrinsically the same nor are they treated in the same way. Type 1 diabetes, once fully developed, involves a pancreas
that *no longer produces* insulin, while type 2 diabetes occurs with a pancreas that *isn’t making enough* insulin or the body resists the insulin. Type 2 diabetes is stereotypically known for developing in people who have been or are currently considered obese (though genetics play more of a factor in the development than this) (ADA, 38). Interviewee 19 makes the point that, “there are two completely separate diseases when you say diabetes. No one chooses diabetes, no one wants it regardless of what type it is or what their situation is and to say so is ignorant, wrong and rude.” This sentiment is repeated throughout the responses with impressive frequency. A type 2 diabetic, depending on the severity of the illness, can take pills to manage glucose levels and can help (not cure) the situation with diet and exercise in some cases.

**Hypoglycemia and Hyperglycemia**

Type 1 diabetics must maintain a healthy balance of sugar in their blood in order to keep their body energized and to keep all organs working properly. The symptoms of blood sugar changes, just like brain structure, are extremely unique from person to person. When broken down, hypoglycemia is three combined Greek words: hypo (under), glykys (sweet) and haima (blood) (Gower 76). Hypoglycemia occurs when the brain is deprived of essential glucose levels. The symptoms of low blood sugar reported in sources and revealed in the interviews conducted include (but are not limited to), excessive hunger, anxiety, confusion, loss of coordination and dizziness (Gower, 77). When there is too little glucose in the body to balance the amount of insulin, the body can temporarily live off of fat and protein stores. The brain, however “can’t use fat and protein for energy...the brain needs glucose to survive [and] regards a sugar shortage as a crisis” (Gower 76). When asked about how experiencing low blood sugar felt physically, several of the type 1 diabetics that I interviewed mentioned that they are hypo-
unaware, meaning that they are unable to feel a low blood sugar until it has reached a more critical stage. “Overall,” Interviewee 9 describes, “It's a lot more work to function normally and to appear that everything is fine. As I go lower, functioning gets harder and getting food steadily becomes the only priority regardless of what I have to do to get it”.

The opposite issue of hypoglycemia is hyperglycemia. Hyperglycemia is essentially too much glucose in the blood with the Greek word hyper (over) beginning the term instead of hypo (under). Interviewee 7 described one of the common symptoms of high blood sugar, vividly stating feeling “slow and sick, like goop is flowing through [her] veins”. Symptoms of hyperglycemia include an increase in appetite, weakness, blurred vision, headache, nausea and/or vomiting.

**Complications of Long-Term Diabetes**

According to the 5th edition of the American Diabetes Association’s *Complete Guide to Diabetes*, “In people with diabetes, excess glucose stays in the blood and may also damage different parts of the body, such as blood vessels and nerves” (ADA, 15). Uncontrolled blood sugar affects the entire body, leading to elevated risks for complications depending on how long the person has been diabetic and how controlled their blood sugar is over time.

If a person is diagnosed young, the actions they take during childhood can affect their health as they get older. The “...complications of juvenile diabetes during adulthood can include kidney disease, heart disease, and damage to the blood vessels in the eye, potentially leading to blindness. Thus, there are both short-term and long-term health-related incentives for maintaining good control” (C.Clark, 8). Interviewee 7 was diagnosed when she was 9 years old and rarely had control of her elevated blood sugar: “I developed kidney disease from my lack of control”, she remembered. Though there are many short term effects when a diabetic is
experiencing a low, such as seizures and confusion, the most commonly damaging long term issues come from years and years of hyperglycemia. The most common worry from the parents’ interviews was described as their child “dead in bed” from an unnoticed low blood sugar during the night.

The complications of diabetes run the gamut, affecting multiple organs. Retinopathy is a condition that affects the blood vessels in the back of the eye, which can lead to eventual blindness in some diabetics. Interviewee 22 described one of his horrific encounters with excessively high blood sugar. When asked what the scariest moment as a diabetic was for him, Interviewee 22 recalled, “The morning that I woke up with blood in my right eye from a retinal bleed.” It is important to note that this particular interviewee was the oldest diagnosed who participated in the project and has seen the most changes in treatment of high sugars. Due to the treatments still having elements of guesswork, Interviewee 22 reflected on how “…the expected life of a newly diagnosed in 1970 was 18-25 years after the date of diagnosis.”

According to the American Diabetes Association, high blood sugar can lead to diabetic ketoacidosis (DKA), where lack of insulin becomes so dire a situation that the patient can die. DKA can manifest through hyperglycemia, ketosis, acidosis and dehydration. Often, type 1 diabetes is diagnosed only after a person was hospitalized for the symptoms of DKA. Interviewee A, a mother, described her child going into DKA while camping in northern Minnesota: “She went into DKA and we didn't know what DKA was. Had we tried to drive from Hinckley to the Twin Cities we would have lost [her]. The closest hospital was 40 miles away. She was then in ICU for 3 days.” High blood sugar can also lead to harming unborn children, causing miscarriage for diabetics who are pregnant. Another serious complication is peripheral vascular disease which damages blood vessels and may lead to foot or leg amputation.
The Day to Day for the Modern Diabetic

The day to day life for the modern diabetic is full of routine (assuming a first world viewpoint and modern treatment systems). Diabetics must keep track of the sugar in their blood with small blood tests throughout the day, which is usually done with a lancet and a glucose meter. Some diabetics have a constant glucose monitor which is a sensor placed under the skin (replaced every 5 or so days) that communicates with an external device that shows the glucose levels and trends. There are correction doses of insulin (different for every patient depending on how sensitive you are to insulin and what your blood sugar range is), delivered through needles or a small cannula in the skin attached to a device called an insulin pump (which supplies a continuous drip of insulin replaced every 3 to 5 days, but requires that you are “hooked up” for most or all of the day). Whenever a type 1 diabetic eats (and if the blood sugar is high or in range), they must take a certain amount of insulin for the carbohydrates in the food.

Michael Weiss, former Chair of the American Diabetes Association and author, states that “everything you eat and do - every minute, every hour, every day - affects your diabetes. The 24/7 intensity is part of what makes diabetes so different from most other diseases” (Weiss, Funnell, 19). Not only is diabetes a time-consuming disease, it is also emotional and consequently, exhausting. Detailed in The Little Diabetes Book You Need to Read, Marti, a diabetes educator describes that “those who took charge of their illness did better, both emotionally and physically” (Weiss, Funnell, 23). It is incredibly easy to become overwhelmed with not only the diagnosis of type 1 diabetes, but also the day to day care. The average healthy person can easily write off what they eat, how they exercise or how they pay attention to the rhythms of their body if they choose to, but a diabetic does not have that luxury. Interviewee 13 describes a stage that many go through when it comes to caring for their diabetes, “I just stopped
caring. I wanted to be like everyone else, so I stopped testing my blood sugar and taking my shots correctly when I could get away with it.” With so many routines and things to keep track of, this is not an uncommon sentiment. When everything bodily is boiled down to a science, with constant numbers running through their heads, carbohydrate counts, insulin dosages and calculating how much insulin it will take to bring down a high blood sugar or how much orange juice it will take to bring it back up when you overcorrect, any diabetic can turn into an amateur mathematician.

**The Varying Emotions of Diagnosis and the Life Afterwards**

Treating a chronic illness as though it were *just* an illness or simply “...a biomedical or physical event, without taking into account the broader expressive and social disruptions...defeats understanding” (M. Clark, 140). It is hard for people to see past the needles and the treatments, the *physical* pain, making the emotional responses of those affected lost or rarely thought of.

There are several factors that affect how a person feels about their diagnosis. With an active support system of family and friends willing to learn alongside them, many feel hopeful about life after the diagnosis. Personal conduct and emotions may play a part in how treatment is handled afterwards when the person is old enough to care for themselves instead of relying on a caregiver. According to a 2012 study published in the *Journal Of Child And Adolescent Psychiatric Nursing*, “adolescents who were more straightforward, honest, and cooperative were more likely to follow their medication regimen” while those who respond with anger or depression related and unrelated to the diabetes struggled with their daily treatment (Wheeler, Wagaman, and McCord, 72). Attitudes towards treatment and medical authority can help or hinder the patient’s diabetes. If diagnosed young and in teenage years, those who are “growing
into adulthood...have occasion to build large parts of their personal identity around their diabetes and to carry with them lessons and values they learned as juveniles. Whether these once-young patients went on to embrace or defy medical authority, their subsequent mature views and behaviors hearkened back to their early experiences in the diabetic world and their initial encounters with physicians” (Feudtner, 177). For some, diabetes becomes an intrinsic part of identity but this is only once it is embraced as a part of life. No matter the age, “nearly two thirds of people with diabetes say they have skipped glucose testing at one time or another because they don’t like pricking themselves” leading to slight neglect of the illness (Gower, 33).

Of the emotional reactions to a diagnosis of type 1 diabetes, denial can prove to be the most damaging. It is found that “people who deny that the problem exists will not take steps to treat the condition and poorly controlled diabetes can lead to any number of short-term and long-term complications” (M. Clark, 33). Denial is a coping mechanism that works to some degree when it comes to suppressing emotional responses, but when the denial affects the daily treatment of a diabetic, their physical health is sacrificed instead. Denial comes in varying degrees of severity and is most common immediately after a patient is diagnosed.

Children circumvent the denial by accepting a very basic definition of the change in their life. When children are diagnosed, they tend to define their diabetes by their treatment routines. In a study conducted by Cindy Clark, when the child subjects are asked what diabetes is, they report that it is when they have to take shots or can’t eat sugar as opposed to saying anything close to the medical or bodily definition (C.Clark, 11).

Frustration is a multi-faceted emotion that comes with the diagnosis of diabetes. Some become frustrated if medical personnel either throw them into the new world too quickly or don’t seem to empathize with the situation. When a child stays in the hospital for a time after the
discovery of the diabetes, the caretaker of the child is immediately shown how to draw insulin, give shots and keep their child alive until they are old enough to do so themselves. Frustration can also develop with the stress of a new routine, or even the effort it takes to maintain that routine. Diabetes is a disease that can never fully be out of mind for very long, as forgetting it even for a moment, seems too dangerous for many. Interviewee 8 described the frustration she felt not only with diabetes, but also with how other people treated her after her diagnosis. “I got bullied one time in high school,” she recalls, “It made me so angry - why would someone pick on me for this? I didn't DO anything to deserve it.”

Parents may feel varying degrees of frustration if their child is diagnosed young. The parents/caregivers play a major role with their diagnosed children, whether they fall into the coping categories of “over-indulgent” “over-protective” or “indifferent” (M. Clark, 65). Frustration with the disease is common with the people that must conduct the treatments and care, which tends to be parents with younger type 1 children. Based on the most common responses from the interviews conducted with the parents of young diabetic children, parents feel a lack of support from teachers and other adults that have the child in their care for much of the day. Interviewee D expressed that “very few [teachers] took the responsibility seriously and did not understand the life and death importance of giving my child sugar when her blood sugars were low.” The lack of understanding from other adults seems to be a predominant source of parental frustration.

The fear that comes with diabetes may not necessarily go away once a person falls into their own treatment routine. Extreme fear centering around diabetes in a patient may also indicate to a doctor that they are suffering from depression. Diabetics that are anxious often have worse control over blood sugars (M. Clark, 34).
Anxiety arises for some when “difficulties and uncertainty loom in the future” (Feudtner, 169). Every diabetic has their her/his own struggles, but common stressors could include the cost of maintaining such an expensive treatment regime. Any diabetic at any age may feel lack of acceptance, even though her/his physical “otherness” is hard to spot based on appearances alone. According to a study by Cindy Clark on the effect of chronic illnesses in children, “cultural institutions like schools, [are places where] a child comes face-to-face with their own exceptionality” (C. Clark, 139). “I knew that I was different,” Interviewee 4 stated when asked about his diagnosis in the early years of grade school. “It was lonely, trying to hide what I was going through. I didn't want others to know that I was different because I was afraid I wouldn't be accepted.” This “exceptionality” manifests in both negative and positive ways in the development of a child diagnosed early, before age 11. Clark continues in her study to say that “treatment of their illness may involve taboo behaviors such as drawing blood or self-injection. Children with illness, even when they follow their treatment regimes to the letter, still suffer from being socially marginalized” which in turn increases diabetes-related anxiety in social situations (C. Clark, 140).

Blame and guilt are both damaging concepts when it comes to diabetes. Blame arises when there is a loss of control. In the doctor-patient relationship, either party can easily point at the other when the frequent endocrinology appointments reveal issues with the illness (Feudtner 190). Feelings of guilt seem more frequent during the adjustment time than during doctor visits, though surprisingly, guilt is often unfounded and expressed by the caretakers of type 1 diabetics. In the interviews, participants were asked how their parents/caretakers reacted to their diagnosis. Interviewee 8 summed up how her “mother felt awful and guilty. Like she had done something genetically and gave it to [me].” Interviewee 9 expressed similar feelings, saying that her
grandma had the most extreme emotional reaction to her diagnosis: “she started crying and apologizing. She's a nurse, and she was absolutely horrified that she hadn't picked up on any of my symptoms. She felt guilty - and I've never really understood that, even now”. The guilt that came from the parents of the newly diagnosed seemed to be turned into hope for a cure for their child as time went on; guilt was an emotion not expressed in a current-sense for many parents interviewed.

**Art and Illness**

The lens through which this project was conducted is entirely my own. What I chose to be visually represented in the interviews came from answers that included imagery that either reminded me of my own close experiences or stood out to me as extreme enough to communicate with an audience that knows little about type 1 diabetes. It has been said that “...no two people view the surrounding world or a work with the same eyes...our attention will be drawn to features of which we have special knowledge” (Sandblom, 13), which made the interviews all the more important to the subject matter handled in the art.. It is important to note that my style is distinctly my own, meaning that my cartoonish depictions, though being inspired by artists spanning centuries, do not take on the formal qualities of the other artists. As mentioned before, the answers from interviewees provide a good launching point for my art, but research based on other artists from the past that depict illnesses also contributed elements to the finished paintings and sculptures. Artists can be inspired to create work relating to illness that is either observed or experienced by them, and several of these artists informed how I carried out the work.

With all diseases, including diabetes, there are many factors that affect those afflicted. “In disease, there is the pain of loss, for which there are no analgesics or anesthetics. It is the loss of
numerous opportunities negated by disease, partially or totally, temporarily or definitively, up to the loss of everything, including life itself” (Bordin, D’Ambrosio 291). For everything one overcomes with a chronic illness, there will always be people putting restrictions on what you can accomplish. These people, surprisingly, are not always medical personnel. The larger oil painting that I completed titled *Can You Eat That?*, refers to the misconception about diabetics that they cannot eat sugar or certain kinds of foods. this was a commonly reported response from non-diabetics to diabetics in the interviews that I conducted. The measuring cups in the painting represent how diabetics must know the serving size of everything they eat in order to dose correctly when taking a shot. The “healthy foods” shown serve as a nod to the people in the interviews that described how many people insisted they could fix type 1 through dietary changes or eating a certain kind of food. This image relates to the day-to-day life of the adjusted diabetic, but other images from the project refer to the diagnosis, as that is the most life-altering stages of the disease.

The hospital stay—the initial moment of a person’s life changing or ending—is an important stage of transition for those affected and afflicted. Due to the fact that “the themes of illness, death, and the end of existence are subjects treated with great importance by the artist,” the beds used in hospitals are transformed into symbols of all three of these elements (Bordin, D’Ambrosio, 47) A hospital or clinic bed can transport you from sickness to health, but also from normative living to a life-altering diagnosis.

Another of the paintings completed for this project, “Anxiety”, depicts a room in a hospital - tacky wall art and all. chromatic black and muddled dark colors surround an anonymous male figure in the right-hand corner of the image. He is sitting on the fateful hospital bed, facing a door that opens to nothing but dark shadows. The fear of the unknown served as a
common theme in several interviews. Interviewee 3 described the initial feelings of dread in the office of the doctor that gave her the news of her diagnosis, “I thought I was literally going to die. Everyone was freaking out, and crying. I know now that I will obviously be ok, but at the time everyone made it seem like these would be my last few days on earth.” Initial reactions from parents were especially emotionally charged, but the people interviewed who were diagnosed young stated that they were initially confused, having to look to their parents/guardians for cues on how to react.

**Contemplating the “Holy”**

There is a kind of surrender in art involving illness. The body is put into a position where it can be acted on by anyone almost without consequence. This submissive state is essential in the doctor/patient relationship. The patient must trust that the doctor knows what’s best for their her/his body. When the doctor can no longer help a patient, the act of surrender is a morbid one. In chronic or terminal cases, the patient surrenders to the disease, or in some cases, a higher power. before modern medicine, most treatments for illnesses consisted of trial and error as “pre-Hippocratic medicine was substantially magic: it was divinities who performed miraculous cures” (Bordin, 174). Scientific methods and procedures now take the place of prayers and spells of healing, but for those with diseases that have no cure, there is nothing yet to fully alleviate them.

The idea of curing through supernatural means, or any force not entirely understood, is an idea belonging to both children and adults, past and present (C. Clark, 141). This idea was especially supported in the realms of early medicine. Before modern medicine and the physiology of the human body were entirely understood, there was a mysterious element that
was labeled as celestial intervention if an illness was cured. Physicians were said to be guided by
god when they succeeded, which is a concept carried over into images of physicians conducting
their practice. According to Cindy Clark’s study on children and chronic illness, prayer is seen as
“...a form of imaginal coping, since it involves the use of the imagination in making contact with
a transcendent, sacred realm” (C. Clark, 140). Imagery in art displaying illness may feature the
afflicted subject casting their eyes upward in a kind of pleading expression (Bordin, Ambrosio,
231). Eyes pointing upward is a sign of significant suffering, showing a reliance of the victim on
something, *anything* to relieve them.

An example of casting the eyes upward during a moment of discomfort can be found in
Goya’s *Lazarillo de Tormes*, which features an adult male examining a child with diphtheria
(Figure 1). This image also includes the suffering caused by physicians, though done for the
overall good of the patient. He shows the discomfort of the boy patient as he is inspected by a
doctor that holds him tightly in place. Many of his paintings depicting darker subject matter
show the suffering and those inflicting the suffering, while this image shows the sufferer and the
man adding slightly more suffering in order to make the situation better. Illness is shown in a
way that told the story of the epidemic that Goya witnessed.

**Goya and the Subject of the Physical Body**

Considered one of the great masters of art, Francisco Goya actively painted from his
eyear teenage years until his death in 1828. How the Spanish artist renders the suffering human
body is of particular interest to me. Though his presentation of the human body in the form of
portraiture is brilliant, his display of the body in motion-and further still, in pain-isa look into
how suffering is depicted in art. Goya produced several works around 1793 depicting members
of the Spanish court (his usual subject matter). Images of mental patients in states of neglect and
anguish, such as his work titled *Yard with Lunatics* completed in 1794, marked a change in his subject matter (Figure 2). Goya adjusts his figures in pain to make them appear slightly less human, almost animalistic, in their varying states of physical and mental suffering. In several paintings, he simply adjusts the clarity of the image, making the eyes less defined or twisting the bodies of mental patients into human balls. To Goya, the patient and “....the world of the insane coincided with that of the unconscious” (Bordin, D’Ambrosio, 168). The discomfort of the patients and victims in his images are emotional as well as phycological.

Goya’s intensely grotesque imagery can also be seen in a set of prints from 1810 called *The Disasters of War* which were “....inspired by the horrors he had seen during the Napoleonic invasion....[which] attacked the criminality of war” (Figure 3) (Halsey, 266). Goya displayed the injured figures and the sick figures of his art much the same way.

It was believed that Goya suffered from lead poisoning caused by exposure to his paints. The artist’s illness rendered him blind, paralyzed and deaf (the deafness became permanent, though he recovered from the other symptoms) (Sandblom, 104). When it comes to the creation of an artwork, “the artist naturally is highly dependent on sensory perception, especially sight and hearing” (Sandblom, 99). Goya’s illness had similar complications that many diabetics dread, the primary example being the loss of eyesight (which is reflected in the piece *13 Eye Surgeries*, named after Interviewee 22 who underwent many procedures to keep his sight).

The remaining signs of Goya’s illness cause his subject matter to take dark, gruesome directions during times of embitterment. The pieces that reflect his suffering are different from the art created from his observations of the suffering of others. Goya shows what he thinks of doctors at an earlier stage of life in an etching with a physician as a donkey, “assisting” the sick artist but actually crushing the man and making matters worse (Figure 4). The image is like a
caricature and features the donkey dominating the composition, uselessly draped over an immobile self portrait of Goya.

Later, however, Goya changes his mind about doctors due to Doctor Arrieta, who attended him in illness in his old age. He “expressed gratitude to the doctor that saved his life” in a realistic depiction rather than an etching that would seem crude in comparison (Sandblom, 128). Goya’s illness was realistically shown in his 1820 painting *Self-Portrait with Dr. Arrieta* (Figure 5). Giorgio Bordin analyzes the appearance of the doctor, stating that:

> To the sick person nothing seems to exist beyond his or her own personal situation, and there is no separation between, on the one hand, the world of actual, objective reality and, on the other, the imaginary and symbolic sphere. So it is that a work like this self portrait can be transformed into a sort of exvoto made for the healing physician, who is seen as a savior. (Bordin, Ambrosio, 71)

Goya’s view was based on specific medical professionals that he interacted with, which was a relatable concept in this project’s interviews with answers to the question, “did you have a doctor or medical personnel that impacted how you feel about your diabetes, good or bad?”

Interviewee 19 was one of the only respondents who expressed an interaction with a nurse that affected her entire outlook on the disease in a positive way. She stated how appreciative she was of this nurse, saying:

> I was really fortunate when I was in the hospital when diagnosed, before I saw the endo [endocrinologist] I had a t1 nurse doing my checks etc, and she said ‘look I want to tell you, the doctors and nurses are gonna tell you to eat this and not eat that and everything, and I've had this for 14 years and I had subway and an ice cream for lunch. Im not a perfect weight either - don’t let it bother you, at the end of the day everything in moderation and making sure you still live your life is what's going to help you through this more than anything else’, and that I think was the best thing ever.” Same changes for extended quote as above.

Through his art showing patients with illnesses that he only viewed as an outsider but also his own struggles with health, Goya shows complexity in his relationship to pain. His work
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at various stages in his career shows the suffering of others but also includes hints of his own emotional and physical suffering. Arguably, the suffering of others that he observed triggered an empathetic response in his work when he depicted torture victims and mental patients in his etchings, but his work surrounding his illness shows his own suffering combined with his frustrations. Philip Sandblom, author of *Creativity and Disease*, argues that the artistic mind wants to understand and connect with other humans so intensely that it must show suffering and the emotions of others, as both seem intrinsic to the human condition (Sandblom, 35).

**The Illness Artists of Surrealism**

Surrealism explores psychology and deals with images derived from the unconscious mind. Both Frida Kahlo and Francis Bacon used the visual language of surrealism. The personal suffering of each artist is often reflected in their her/his work.

Frida Kahlo was a prolific artist with a distinct, surrealist style. Her work includes portraiture that alludes to an injury she sustained in a trolley accident when she was 18. She utilizes a “...magical blend of personal mythology with Mexican folk art” for imagery in her work (Rummel, 159). Some of the treatments she endured included spinal injections and eventually, blood transfusions for assumed syphilis (Rummel, 154). Later in her life, her right foot and most of her lower leg was amputated. In his book, *Frida Kahlo: A Spiritual Biography*, Jack Rummel pinpoints one of Kahlo’s well-received portraits that displays her lifelong medical issues. He analyzes her painting *The Broken Column* (1944) through an empathetic and emotional lens (Figure 6):

“Frida found a way to express her response to physical suffering in the painting *The Broken Column*, completed in 1944. In it she paints herself strapped to one of the corsets that Dr. Zimbrón had prescribed for her. She is naked from the waist up and a sheet reminiscent of a hospital bedsheet covers her hips and legs. Nails
tacked into her body indicate pricks of pain. But the most dramatic aspect of the painting is her visualization of her wounded spine. She imagines it as a broken ionic column. In spite of the tears covering her face, Frida looks straight at the viewer appearing almost brazen. Her features are expressionless and stoic, and she holds herself proudly upright. This is the face she wants to present to the world about her physical pain. (Rummel, 159)

Kahlo uses extreme examples to show physical pain. The nails take the place of individual hotspots and nerves, with the constricting corset and figure in the foreground creating a claustrophobic presence and pressure on the audience.

Shown in Kahlo’s art are her day to day thoughts about her condition. Her obsession with fertility and fertility-ridden images are especially present in the sketches within her diary. One of her last entries in her diary, however, features minimalist drawings. She writes about her illness and the many doctors that tried to alleviate some of her suffering:

Thanks to the doctors Farill - Glusker - Parresand Doctor Enrique Palomera Sanchez Palomera Thanks to the nurses to the stretcher bearers to the cleaning women and attendants at the British Hospital -Thanks to Dr. Vargasto Navarro to Dr. Polo and to my will- power. I hope the exit is joyful - and I hope never to return -FRIDA (Lowe, Fuentes 179).

Her use of local color with a surrealistic twist inspired my image titled Can You Eat That?. Kahlo “transmuted pain into art with remarkable frankness, tempered by humor and fantasy” (Sandblom, 13), which was an attitude I tried to reflect by displaying a simple still life of food, measuring cups and the elephant in the room, or rather in the cup, a syringe.

Directly influencing this image of mine are still lifes that Kahlo completed during her career. Kahlo includes a small part of the image that is either not entirely true to life or slightly disturbing. In one image of fruit, titled Fruits of the Earth, the way she positions the fruits and vegetables creates a skull-like image towards the lefthand side in the middle-ground of the painting (figure 7). Her limited palette of brown, diluted greens, and a glowing red featured only
in the center of the image, creates a plate that could be idolized but also a feeling of something lurking unseen in the subject matter. The fruit is ominous without having to be *obvious*. For my still life I used local color including the syringe that seems unnatural yet is taking the place of a straw that would naturally belong in the scene. Both a straw and a syringe hold the same cylinder shape and deliver liquids into the body, yet it would be extremely unnerving to find a syringe in a drink. This small element that seems out of place in the scene was my visual response to Interviewee 8 who stated, “People will never truly understand how HARD it is to live with this every second of the day.” It is constant, it never fully goes away and it never leaves your consciousness, yet it is normalized. It’s hard to read fruit as “fruit” visually and not calculate the carbohydrates and possible complications to blood sugars. This particular painting is also inspired by another of Kahlo’s still lifes, *How Beautiful Life is When it Gives Us Its Treasures*, which uses richly saturated colors on the sliced watermelon, oranges and coconut while also confronting the viewer with a seemingly out of place image to the right of the painting (figure 8). On the far right edge, a clock sitting atop a book is present in a way that makes it belong in the image as though it were a fruit itself. The clock’s form fits with the collection of the overlapping fruits created out of variously sized circles, extending the shapes to the edge of the painting. Kahlo’s work is capable of these subtle inclusions, though when it comes to medical treatments, Kahlo borrows from the horrific and traumatizing. Kahlo’s *Without Hope* shows her in a hospital bed (again, a powerful symbol by itself), undergoing her version of how she was forced to eat in the hospital (figure 9). The image of the monstrous contraption to feed her bed-ridden body was how the artist showed her exhaustion and emotional response to the countless medical procedures she experienced over her entire life.
I took the idea of a diary that speaks of illness, from which Kahlo derived most of her work and used as a kind of sketchbook, and turned it into a sculpture. *December 1999* is a sculpture that addresses my diagnosis, using my diary (a small, red-covered notebook) from 1999 when I was seven years old, as source material. Kahlo’s diary is a work of art in of itself, which inspired me to make my diary worthy of being placed on a pedestal as well. Kahlo’s diary is her spiritual guide through her artistic ideas, with song lyrics, poems and her deepest thoughts scrawled out on the pages between the small drawings. My diary shows my own journey towards the acceptance of the disease as a young girl, which is similar to the acceptance that I have for the disease in my adult years. The seemingly insignificant red notebook is one of the only times I acknowledge my disease as a part of me; it was not mentioned willingly again until college.

**Francis Bacon and The Human Condition**

Francis Bacon is “stylistically related to both surrealism and abstract art, his work consists of recognizable visual incidents, often taken from photographs” (Halsey, 441). His “frightening distortions of the human figure exemplify human alienation and isolation....becoming screaming mutations” while also showing the themes of physical and emotional anguish (441). Movement and moments of intensity are valued in Bacon’s art from the middle of his career, with “the qualities of improvisation and immediacy, [that] are evident in the smeared and broken brushstrokes [with] ....vivid, non-naturalistic colour” (Hammer, 11). Bacon aims to show “...the universal truth about ‘the universal condition” in his art, and features common themes of screaming, agony, sex and people he cares deeply for, such as his multiple lovers (Hammer, 15). An example of how he rendered those he cared for can be found in *Three Studies for a Portrait of Lucian Freud* (figure 10). All three images feature the same crimson color that dominates the frames. Photorealistic elements that accurately depict a human head are
smeared to the right as though violently grabbed and twisted like putty. His subject has a calm expression compared to Bacon’s usual screaming figures. The dominating reds, paired with minimal streaks of green, gray and black, create a sense of unease as it distorts one of the most important parts of identity for a human.

When it came to creating human figures in my art, I considered including portraits in the project, realistically showing some of the people that I interviewed. In the end, I felt that this would have an alienating effect on the audience. Without a lengthy explanation to go with the images, the idea of suffering and pain may be completely lost. Instead, exaggeration became a tool I used often in my smaller images. Instead of one tube leading from the subject’s body in Tube Girl, I chose to use countless [tubes]. The idea I wanted to convey needed to emphasize the amount of supplies diabetics actually use. The color choice is intended to depict a battle going on within the girl’s body, with the calm blue being forced away by the contact points of the tubes and the warm reds. Her internal circulatory system is forced to be made external in the painting. The body is fighting itself to the point of destruction, with the treatment for the problem also appearing detrimental to the subject. For two of the paintings, I also played with distorting the human proportions of the subjects to further feelings of anxiety. The subject of this painting is passive, with a lowered chest cavity and hunched position. Her head to body ratio is more reflective of a child’s, and her body is swollen from the obscene number of needles.

Bacon’s art rarely features subjects that aren’t in some form of implied motion and he is very intentional with his use of color. His Study for the Head of George Dyer shows the distorted profile of a man against a solid green background (figure 11). The subject is made of cool and warm colors unapologetically smashed together rather than blended. This portrait seems to have an unusually calm expression compared to Bacon’s other work, and ultimately helped me make
the decision that *Tube Girl* should borrow ideas from Bacon, but not be screaming. The inner struggle is made apparent by the fighting primary colors coursing through her body instead of an outward explosion.

John Berger, quoted in the book *Francis Bacon, Portraits and Head*, observed how “He [Bacon] repeatedly painted the human body or parts of the body in discomfort or agony or want. Sometimes the pain involved looks as if it has been inflicted; more often it seems to originate from within, from the guts of the body itself, from the misfortune of being physical” (Hammer, 25). The “misfortune of being physical” especially applies to a disease that rarely has symptoms easily recognized by the public. Diabetics can suffer, but it might not necessarily *look* like they’re suffering. Even then, Interviewee 3 pointed out that “they [the public] only see the physical side,” often negating emotional struggles that go hand in hand with the physical.

When it came to showing how highs and lows physically felt within my series of paintings, Bacon informed how I chose to show the profile images of human heads. The “high head” and “low head” literally have wax melted over them, which involves his melting aesthetic in a more literal way. Francis Bacon’s images are direct and confrontational, drawing attention to elements through his use of exaggerated proportions and colors. His use of black and white images and composition also informed my acrylic painting *Weighs on My Mind*, which has a distorted, colorless background similar in style to his *Figure Study II* (figure 12). This colorless background was my way of making the important elements of the piece (the insulin and candy) stand out.

**Personal Suffering, Personal Portraits**

Hannah Wilke is primarily known as a performance artist who used her body as her medium; sometimes combining sculptural elements with her body. When she was diagnosed
with lymphoma, her art became focused on self portraits as she underwent treatment for her illness. Her project, titled *Intra-Venus*, is meant to draw attention to medical procedures that are usually not talked about or thought about. Through photographs, sculpture and performance art, the project shows [documents?] the last two years before her death.

What I take away from the *Intra-Venus* photographs is that treatments, however extreme, should be shown. The needle *should* be in frame and the doctor’s office *should* be shown instead of hidden away as though illness deserves to be socially shamed. A disease that is chronic and deadly affects someone to the point that that disease, for better or worse, is essentially a piece of the person and their history.

In one of Hannah Wilke’s photographs, she shows the hair shed during her cancer treatments (figure 13). In my sculpture, *I Knew When*, the idea of presenting a part of the artist was inspired by Wilke’s piece. Hair doesn’t apply to diabetes, but blood does. All of the strips in the sculpture have blood in them, showing not only the waste of the supplies that accumulate but also the essential waste of bodily fluids. While the sculpture deals with history, it also deals with bodily treatments for the disease. I went for a more playful route with an ant created out of test strips approaching sugar on legs fashioned out of syringe plungers to show the history of diabetes. When ants would flock to a patient’s urine, the doctor would notice the excessive amount of sugar that attracted them. The sculpture combines the way sugar in the body used to be detected and how it is detected now, while also having the facial structure of a honey bee serving as a small nod towards the history of diabetics and their “honey sweet” condition. Including actual blood in this, a very powerful symbol and indicator of some kind of bodily harm when visually depicted and actively a part of an art piece, is a way to show that I am by no means trying to “sugar coat” the entire disease, while also including an actual part of my body.
Wilke attempts to display disease as it is with elements of lightheartedness set against the devastation of a body wasting away. Wilke’s image of herself in a two-paneled piece from the *Intra-Venus Project* shows her with bandages on her hips, fully nude and balancing a flower-filled vase on her head (figure 14). This photo struck me as goddess-like with her assertive pose, even in times of pain. These ideas clash together in *Tube Girl*, which was created from images of myself, though not necessarily meant to only represent me. There are struggles with diabetes that affect women in ways that men can’t experience physically, such as miscarriages, so I felt it was important to have the figure be female and slightly alien to the viewer (she could potentially play the role of deity in her otherworldly appearance while also remaining in an almost reverent pose to that which is keeping her alive). Though Wilke’s images of her personal struggles are black and white, mine are color and use a completely different medium. Wilke’s decision to have herself photographed in black and white gives the images a timeless feel that had the ability to carry on after her death. Hannah Wilke documented her cancer, but also her mother’s cancer which is summed up in a review of the images in a gallery held after her death: “Wilke believed in the potency of the image. She spoke of hoping to save her dying mother by capturing her spirit in photographs. Pictures did not save her mother’s life, nor her own” (Daigle, 2).

The images are fitting as a project of remembrance and to show an illness as it actually is with barely any decorative elements included. The emotion is felt through the images with the background knowledge that the artist’s disease is terminal. A sculptural piece that Hannah completed in 1992 titled *Why Not Sneeze...?* (figure 15) features medicine bottles and syringes in a wire bird cage. This sculpture doesn’t rely on portraiture to get the message across like her previously mentioned photographs. This simple concept conveys the idea that medical routines and illness are essentially a influence the life of the diagnosed. Not only is illness shown as
inconvenient by this sculpture, but it is also shown as limiting and confining to the artist. Why Not Sneeze...? ties in directly with my sculpture of an orange skewered with needles and broken glass titled Supplies. Both sculptures utilize actual tools used in the treatment of an illness while also combining non-medical imagery, such as the orange or the birdcage, into the work. This final project before her death in 1993 not only shed a light on medical processes and their negative effects, but also showed that Hannah Wilke would not be abandoning creativity just because of a terminal diagnosis.

**Conclusion**

Through the influence of other artists that depict their own suffering and the suffering of others, and the responses to the interviews I conducted, I am inspired by the thirteen pieces that I completed so far to continue with this project. Through this portion of the project, I have been able to express my own experience as a diabetic and also the feelings of others with the illness. From diagnosis to day to day care, the challenges (though diverse) are always present with those fighting this illness. By representing the personal experience of the diabetic and drawing inspiration from other artists who witnessed illness themselves, I have reflected extensively on diabetes artistically and have exposed a wider audience to the emotional effects that are so much more than the medical treatment of an illness.
Figure 1-Francisco José de Goya y Lucientes (1746–1828).

*Lazarillo de Tormes* (1819). Oil on canvas. Private Collection,

Figure 2-Francisco de Goya, *Yard With Lunatics*, 1794,

12.9 in × 17.2 in, oil on tinplate. Meadows Museum, Dallas
Figure 3-Francisco José de Goya y Lucientes, The Disasters of War, pl. 37: "Esto es peor (This is Worse)", 1812-1813, etching, 157 x 107 mm.

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Figure 4-Francisco José de Goya y Lucientes, *De que mal morira? (Of What Ill Will He Die?)*, 1799, 21.5 x 15 cm, etching and aquatint. Fine Arts Museum of San Francisco, California.
Figure 5-Francisco José de Goya y Lucientes, *Self-Portrait with Dr. Arrieta*, 1820, 45 1/2 x 31 3/8 in, The Minneapolis Institute of Arts, Minnesota

Figure 6-Frida Kahlo, *Broken Column*, 944 40 by 31 cm, oil on canvas, Museo Dolores Olmedo Patino, Mexico City.
Figure 7-Frida Kahlo, *Fruits of the Earth*, 1938, oil on masonite, 16 3/4 x 23 1/2. University of California, San Diego

Figure 8-Frida Kahlo, *How Beautiful Life Is When It Gives Us Its Treasures*, 1943, 39.6 x 48.7 cm, oil on board, University of Texas, Austin
Figure 9-Frida Kahlo, *Without Hope*, 1945, oil on masonite 11x14.25, University of California, San Diego

*Hope*, 1945, oil on masonite 11x14.25, University of California, San Diego

Figure 10-Francis Bacon *Three Studies for a Portrait of Lucian Freud*, 1964, 14in x 12in each. Oil on canvas in three parts. Private Collection.
Figure 11-Francis Bacon - *Study for Head of George Dyer*, 1967 oil on canvas, 35.5 x 30.5 cm. Private Collection.

Figure 12-Francis Bacon, *Figure Study II*, 1945-46, 57x50.6’, oil on canvas. San Diego, California.
Figure 13-Hannah Wilke, *Brushstrokes*, 1992. Artist’s hair on Arches paper: 33” x 25 1/2”, New York
Figure 14-Hannah Wilke, Single image from two paneled Intra Venus. Photo by: Dennis Cowley. Ronald Feldman Fine Arts, New York.

Figure 15-Hannah Wilke, Why Not Sneeze...? wire bird cage, medicine bottles and syringes 7 x 9 inches

Works Cited


Appendix A
Project Reflection

When it came to choosing a topic for this project, I wanted to incorporate my major in Studio Art, but also my life experiences. I wanted a topic that I had knew the basics of already and could expound on, so I decided to focus my work on depicting type 1 diabetes though artistic mediums. This project started from conversations I had constantly with my diabetic friends. I could hear common themes in these conversations of frustration with the lifestyle needed to control diabetes and the lack of understanding from others. I also brought in many elements of nostalgia for me and was transported back to my own diagnosis 15 years ago. When I began the interviews, I reached out through online support groups to see if anyone would be willing to share their stories of diabetes with me. The response from people excited to be interviewed was overwhelmingly positive, and I found that many parents wanted to be interviewed as well about their diabetic children. The concept of emotion in the project came from the heartfelt responses I received from the caretakers of diabetic children.

Being able to create an image based off of some of the interviews proved to be difficult. At times, it was difficult to come up with a drawing for the quotes that struck me. My saving grace was allowing myself time to create without having to force the art to meet the deadlines. The art portion came naturally, while the research portion seemed the most tedious and time consuming overall.

Until this project, I had never set up a gallery before. My first attempt, I was armed with poster hangers and was very conscious about not leaving any signs of my presence on the gallery walls. After several hours of having a completely finished gallery, every single one of my
paintings fell onto the floor. My second attempt, I decide nailing everything up would be a safer approach.

Another challenge that I faced throughout the entire process was a combination of time management issues and a full work load. Being generally inexperienced with oil paint, I didn’t realize the time layers and layers of it would take to dry. The paint was still drying on one of the canvases I hung in the gallery (which didn’t fare well when all of the pieces fell down). In my original plan, I was expecting to have paintings that were much, much larger instead of the standard size I used for all. I was also inexperience when it came to IRB processes (the review board that determines whether or not a study is able to use human subjects). It was like a crash course in both the arts and the sciences all at once.

My main challenge, however, was the construction of the paper portion of the project. My original idea for my project didn’t involve the study of other artists, so trying to find specific ones that depict illness in their work was difficult. Finding art that actually inspired me was even more difficult. Eventually by spending time with the artists, I got to know the pieces that I could identify the most with and relate to my own style. Thanks to my advisor, my outline was drastically altered to include the sentence “to be determined by the artistic process”, which let me continue to be creative with the project under guidelines built for projects more inclined towards the sciences.

Originally with my paper, I had the idea that I was going to be able to have at least 40 pages when all was said and done. Not only did this create pages and pages of unnecessary filler, it also made the process of editing a complete nightmare. It’s hard for me as a person with diabetes to know what the general public understands and does not understand about the disease, so I spent a dozen pages explaining every aspect of the disease until the topic was exhausted.
I plan on continuing this project in the future. I feel that I owe at least a drawing to every single person I interviewed. Finding something that inspires me to create an entire body of work is rare, so I feel that working on this project and refining my style through it will be beneficial to my art. Continuing to work on this project will help me expand my knowledge on the experiences of others as well. I’m only an expert in diabetes when it comes to my specific situation, and I’ve found that there is always more to learn besides the strictly medical terms. I plan on naming future diabetic works after statements in the interviews, as I felt that was one of the main ways to tether my vision and inspiration to the experiences of others.

From this project, I learned the importance of making timelines for myself and sticking to them. Procrastinating was not an option with this project, especially with all the collaborative elements included. I am proud of the final work that I displayed in the gallery, but I hope to continue producing work that uses everything I learned from this experience.
Appendix B
My Work

*High Head*  
*Low Head*, acrylic and wax on canvas panel

*The Playroom*, acrylic on canvas panel
Tagged, acrylic on canvas panel

I Knew When..., mixed media (test strips, syringes, hot glue)

Can You Eat That?, oil on canvas
Weighs Heavily on My Mind,
acrylic on canvas
13 Eye Surgeries, acrylic on canvas panel

Tube Girl, oil on canvas
*Supplies*, mixed media
(balsa foam, paint, syringes, glass)

*December 1999, mixed media*
Anxiety, oil on canvas

Gallery setup, March 11 2014