Beyond the Diagnosis: A Photographic Inquiry of Chronic Illness

Alexandra Monroe

Faculty Advisor: Lisa McCarty
Rubenstein Library

Submitted Date: April 2017

This project was submitted in partial fulfillment of the requirements for the degree of Master of Arts in the Graduate Liberal Studies Program in the Graduate School of Duke University.
Abstract

The old adage for authors is to ‘write what you know,’ and I believe the same can be said for any other artistic medium. I was diagnosed with Irritable Bowel Syndrome about four years ago and it has been a life-altering experience for me. I now have to shape the rest of my life around the management of a medical condition that forces me to locate the nearest bathroom whenever I go somewhere new, carry medication with me at all times, and cook everything I consume. I have struggled with this new way of life, and wanted to help remove stigma while building connections with others. It finally occurred to me that I could use my passion for photography to document the experiences and stories of myself and others with chronic illness.

The main portion of this project is a website, www.monroephotos.com, that shows photographs I made with each individual as well as a portion of the story behind their illness. I struggled to give a name to this project but I ultimately decided on Beyond the Diagnosis because it implies that there is a story to tell after a diagnosis of chronic illness, and that an authentic life can be lived in the face of illness. And, as I will outline in the paper component of this project, there is real world evidence and scholarship that examines the need for a reclaiming of the self after facing a life-altering diagnosis.

The project provides a window into the lives of five survivors of chronic illness beyond what is detailed in their patient charts – they are more than their diagnosis. With the contributions of my collaborators- Kevin, Eleri, Sam and Alex, as well as my own story- the website and paper explore the ways in which chronic illnesses impact the daily lives of each participant.
Contents

Abstract ........................................................................................................................................iii
Acknowledgements .................................................................................................................. v
Introduction................................................................................................................................... 1
  Eleri ............................................................................................................................................... 2
  Kevin ........................................................................................................................................... 5
  Sam ............................................................................................................................................. 7
  Alex ............................................................................................................................................. 9
  Alex M ......................................................................................................................................... 10
Agency through Identity ............................................................................................................. 12
Documenting Illness as an Outsider ............................................................................................... 13
Documenting Illness with an Ill Body ............................................................................................ 25
Chronic Illness’ Place in Society .................................................................................................... 31
Looking Forward............................................................................................................................ 38
References ..................................................................................................................................... 39
Acknowledgements

I want to extend a thank you to a few people who were instrumental to the completion of this project. To all of my collaborators, Kevin, Sam, Alex, and Eleri, thank you for your willingness to work with me and share intimate details of your lives. I feel very privileged to have been welcomed into your homes to document your journeys which have impacted me and my own perspective on illness. To my advisor, Lisa McCarty, thank you for all of your help and support in making this project reflect my vision, one which I often could not verbalize on my own. Thank you to Donna Zapf, Kent Wicker and Dink Suddaby for fielding all my questions and guiding me through the thesis process. Finally, thank you to all the friends and family who supported me during this endeavor; my parents for making my time at Duke possible, and my fiancé Charlie who encouraged me to challenge myself and made it possible for me to travel and work on this project whenever I needed. Thank you everyone, I couldn’t have done it without you.
Introduction:

Being diagnosed with a chronic illness is a life-changing event and can impact people in unimaginable ways. It is important to establish what exactly qualifies as a chronic illness and some of the implications of such a diagnosis. WebMD states that:

A chronic illness is a condition that lasts for a very long time and usually cannot be cured completely, although some illnesses can be controlled or managed through lifestyle (diet and exercise) and certain medications. Examples of chronic illnesses include diabetes, heart disease, arthritis, kidney disease, HIV/AIDS, lupus, and multiple sclerosis... Serious illness can cause tremendous life changes and limit your mobility and independence. A chronic illness can make it impossible to do the things you enjoy, and it can eat away at your self-confidence and a sense of hope in the future. No surprise, then, that people with chronic illness often feel despair and sadness. In some cases, the physical effects of the condition itself or the side effects of medication lead to depression, too. (WebMD)

Because the kinds of diseases that fall under the category of ‘chronic illness’ are so varied there are different limitations that each person will encounter. However, some examples of lifestyle changes include multiple medications a day, frequent doctor/hospital visits, dependence on canes and many other challenges that often lead to severe lifestyle modifications.

The first portion of the project, the website (www.monroephotos.com), will provide insight into chronic illness as experienced by my collaborators and myself through words and photographs. The second portion, this paper, will examine some scholarly frameworks that can assist in interpreting the website’s content. These topics will include: Agency through Identity,
Documenting Illness as an Outsider, Documenting Illness with an Ill Body, Chronic Illness’ Place in Society, and Looking Forward beyond the project’s current parameters.

While the website includes a selection of images that resulted from collaboration between each individual and myself, the following photographs were planned out by each person on their own and I merely captured their vision.

Eleri:

I have worked with Eleri for a few months now and learned a lot about how her arthritis has impacted her lifestyle. She had severe swelling and stiffness in her ankles, but since the treatment she has been able to run and is now on her school’s track team. Each week she fills me in on what she was able to achieve (one week it was hurdles, the next relays) and she monitors her treatment’s effectiveness using the times recorded when she runs the mile. 12.12 is the time before she was diagnosed, and now after a few years of correct treatment she is down to 6.41.

Before Diagnosis, North Carolina, 2017, Eleri Reyman
While at the hospital, Eleri said that she wanted to take photos of the needles and the biohazard sign on the needle collection bin. Since she was unaware that an IV line would be placed on this visit, I decided to take a photo for her and this was her favorite.

I often have to remind myself that Eleri is only 12 years old, especially when she is speaking about her arthritis or medical treatments. She carries herself with a maturity that comes from a
tough diagnosis and severe physical limitations very early on in life. That’s why this image is my favorite—Eleri wore skinny jeans to the doctor’s appointment and since they had to examine her knees and ankles the nurse gave her a pair of disposable pants to wear. After the appointment she acted like a typical twelve-year-old put them on her head and requested that I take her picture.

Disposable Shorts as a Hat, North Carolina, 2017, Alexandra Monroe
Kevin:

When I asked Kevin about what kinds of medications he has been prescribed he brought me to the bathroom and brought out all of the ones that he still had. Bag after bag emerged from the cabinet and the pile on the sink grew larger and larger. These were simply the most recent medications and he has been off most medication for his back for years now.
When we spoke about his cane and how often he uses it he brought a few out to show me the collection. I thought that perhaps he had purchased these decorative ones as a stylish accessory—why not have a colorful cane instead of a metal one? Instead he informed me that he had to buy the dark brown cane at Disney because he had been using the yellow one on his recent visit when he heard a cracking noise. Because he has to put his entire body weight on the cane to support himself and walk around, the wood of the cane simply could not handle the pressure and it cracked. Kevin showed me the big split down the middle and told me that he had to go into a shop and buy this new cane…“other people buy souvenirs at Disney and I end up buying a cane so I can walk.” He placed the canes on the door overlapping each other and thought it would make an interesting image.

Kevin has always been a big fan of Rock and Roll, and he has the T-shirt collection to prove it. The guitar poster and his prized possession-an electric guitar with Jimmy Hendrix emblazoned on the back-rest next to the bed. The family dog, Remy, scratches at Kevin’s leg to go for a walk and because Kevin is his favorite.
As with most actors, a stack of playbills and ticket stubs can be found on Sam’s dresser, along with a medal from the Jingle Bell Run for Arthritis. Sam’s involvement in the arthritis community has been greatly benefitted by her fellow actors in graduate school, along with her professors who have also made generous donations. Sam soaks up life in New York City the way most 24 year olds would despite battling multiple difficult diagnoses at once.
When I first spoke to Sam about the project, her initial response was that her room looks like it could belong to anyone else her age, until you see the large pill box filled with nine different pills a day.
Alex:

Living away from Florida has definitely been an adjustment for Alex, but her orange placemat that says “Home” on a silhouette of Florida brightens her kitchen counter. When we spoke about her medication, she brought me a stack of inhalers that she keeps handy. The Advair prevents Alex’s lungs from spasming and keeps her airways open, while a different inhaler provides steroids to soothe her bronchioles.
Me (Alex M):

I struggled with visually representing my severe dietary restrictions because everything I did was simply uninteresting as a photograph. However, this image shows the limitations that are in place when I go out to eat. The red marks indicate thing I would have to substitute to be able to order that item. While substitution is often possible, I still mostly get sick after eating out which is either due to cross-contamination issues, or waiters who do not take me seriously when I say that I genuinely cannot have any garlic or onion, including powder. I actually once had a chef come out to speak with me and essentially refused to cook without at least onion or garlic powder because it would be too bland... even though doing so would make me horribly sick. I have found that more people take me seriously if I tell them that I have an allergy; then they go from thinking that I’m a picky eater or on the latest fad diet, to being terrified that my airways will close and I’ll need an ambulance. As a result of these reactions I try to avoid eating out at all costs.
I felt that it was important to include these images because they were the explicit vision of each individual. Having the voice of each collaborator incorporated into this project was very important to ensure everyone has agency. This project required each person to reveal intimate details of their lives and pain, and without a sense of agency disclosing this information could leave them feeling vulnerable instead of empowered by sharing their experience. Agency is a very important component of this project.
Agency through Identity:

In creating this project, I struggled with finding an appropriate balance between anonymity and agency for each individual who agreed to work with me. I was initially determined to keep their identity a secret and even if they told me that they had no problem with having their identity in the open I felt I was invading their privacy. However, after much reflection I realized that in removing their names or faces from this project I was not allowing them to be collaborators and equals in this project’s creation. In reading some of the scholarly work on the subject I saw that including their identities was actually essential to the intent of this project— if I removed their names and identities I would be stripping them of their agency. Medical sociologist Arthur Frank writes in his book *The Wounded Storyteller*, about any individual “living with illness for the long term, wants her own suffering recognized in its individual particularity; ‘reclaiming’” (11) their identities after diagnosis becomes an important part of the process. Later in his book Frank writes about a man who had been a part of an article in a medical journal:

I imagined the article might actually be about him: his suffering throughout this mutilating, if life-saving, ordeal. As I looked at the article I realized his name was not mentioned. Probably the surgeon and the journal would have considered it unethical to name him, even though pictures of the man were shown. Thus in ‘his’ article he was systematically ignored as anyone — actually anything— other than a body. But for medical purposes it was not his article at all; it was his surgeon’s article. (Frank 12)

Therefore, to ensure that none of the participants in my project would come to feel as disembodied as the individual that Frank references, I consulted with each person about how
much information they were comfortable sharing. Though I was initially hesitant to share anything personal about my participants, perhaps because in the medical world it is a cardinal sin, to discuss patient information, I found each person was eager to share their story. I began the project feeling intrusive as I asked my collaborators to recount very painful and raw experiences. However, I was put at ease once I sensed that these stories had simply been waiting for a willing listener. This project showed me that there needs to be space to share and examine illness stories; we, the chronically ill, often end up with feelings of isolation and depression because we have yet to carve out a space for discussing our experiences outside of the doctor’s office. Arthur Frank believes that “a person needs others’ stories...suffering does not magically disappear when the tale is told, but the more stories I heard the less space my own suffering seemed to take up. I felt less alone” (Frank xi). This project is a starting point for those very important conversations, and can serve as proof that no one is alone in their feelings on the often difficult journey of long-term illness.

**Documenting Illness as an Outsider:**

Before I began photographing, I explored influential works and perspectives in the history of photography to see how other artists before me had approached documenting illness and narrative. One of the great scholars of photography, John Szarkowski, writes about five key elements of photography in his seminal work *The Photographer’s Eye*. One of these five elements, referred to as *The Detail*, was at the forefront of my mind as I ventured into the lives of people with illnesses that are otherwise unseen to the naked eye. My initial fear in attempting this project was that my photographs would be too commonplace to have any value
to an outside observer. However, upon referencing Szarkowski, I was reminded that according to the element of *The Detail*, “the compelling clarity with which a photograph recorded the trivial suggested that the subject had never before been properly seen, that it was in fact perhaps *not* trivial, but filled with undiscovered meaning. If photographs could not be read as stories, they could be read as symbols” (Szarkowski 3). Therefore, I created a process for working with each person; I would first talk to them about their diagnosis and how their lives changed as a result of being ill, then we would explore their home for objects and signs of modifications that represent the manifestation of their diagnosis. For many of my subjects, objects such as pill bottles or canes are the only outwardly visible signs of their illness. For others, it took a much more attentive eye to identify the subtleties of each person’s daily life that stems from their illness.

This approach to photography—placing the seemingly ordinary at the forefront of the image—can also be seen in Nan Goldin’s work for the book *Hospice: A Photographic Inquiry*. In this piece, Goldin focuses on capturing the mundane in each patient’s surroundings at the hospice facility. The images construct a narrative about the spaces they inhabit during their final days, and because the images are made under specific circumstances, the content becomes even more intriguing. Removed from the context, it appears as though Goldin has photographed without much intention, and alone they are not remarkable photographs. However, once placed in the context of hospice care we, the viewers, understand that Goldin has photographed the private spaces of terminally ill individuals, exactly as they keep them—no more, no less. The spaces and images are not clean and polished; food wrappers pile up on a bureau in one image while another image centers around a countertop cluttered by medicine
bottles. Instead of attempting to modify the rooms to create an image with traditional composition, Goldin simply documents each person’s living area, allowing them to maintain their identity. It would have been easy for her to come into each person’s environment and clean up the spaces in order to create a more aesthetically pleasing image, but in maintaining each space, Goldin allows the rooms to tell the story of the life in hospice. The rooms look lived in, they have real disorder, and we are reminded of the fragility of our own mortality— the living room and bedroom dresser could belong to any one of us, not just these individuals approaching death. In the photograph of the television unit, we see photos and papers stacked by the T.V. where a publisher’s clearing house commercial fills the screen. The table in front of the T.V. unit is covered with the syringes, but it almost becomes an afterthought in this image, reminding us that the patient watching this show is probably in massive amounts of pain (hence the plethora of injections) and they will soon face death.
Joseph’s Medicine, New York City, 1995, Nan Goldin, “Hospice”

Carmen’s Medicine, New York City, 1994, Nan Goldin, “Hospice”
During this project I found Goldin’s work to be an inspiration and it served as a guideline on how to approach a subject’s living space. In any other photo shoot I would certainly move items out of the frame that distract from the subject, such as clothes strewn about, food wrappers, or medicines on the dresser. Yet for this project I found myself drawn to those items and began to consider them extensions of the subjects themselves, or as Szarkowski would suggest, they are symbols of the illness each person is experiencing and help inform the viewer. For someone who is chronically ill, particularly with a mostly ‘invisible’ illnesses, the spaces they inhabit can represent their diagnosis in a way that a portrait simply could not. I attempted to make images that would document what their lives look like on an average day. As my work progressed I came to view the ‘mess’ in each space as a positive element—mess is a sign of life.
and ableness for individuals with physical limitations enforced by their illnesses. A pair of running shoes in the middle of the floor of an asthmatic’s apartment are not a distraction from the subject, or a mess, they are a triumph over the illness that would otherwise prevent them from exercising at all.

This project documents portions of the journeys five individuals embarked on before, during and after their diagnoses. Because a chronic illness is essentially a life-long sentence, and each person’s medical experiences occur over many years of their lives, the photographs and words combine to illustrate only a small piece of this experience. Since chronic illnesses are typically less visually apparent than other diagnoses, the photographs are contextualized by words from each participant to capture the nuances of mostly hidden ailments. This is a concept which Szarkowski touches on when referencing images from the American Civil War that required “extensive captioning, [to show] what was happening. The function of these pictures was not to make the story clear, it was to make it real” (Szarkowski 4). This project uses two mediums, images and text, to make the diagnoses “real” for the viewer. Both elements make the viewer take note of symptoms that might have otherwise gone unnoticed. Words, quotes and captions for images, shed light on the struggle of seemingly endless doctor’s appointments, tests, treatments and regular pain; while the photographs created with the aid of each person highlight the subtleties of each illness in a way that a medical chart never could.

One fairly universal struggle chronically ill people face is that other people make assumptions about their health status simply by looking at them. While I was working with Eleri, a nurse at the clinic asked her if she had hurt her wrist doing gymnastics. In reality, Eleri was about to get an MRI to assess the level of inflammation her arthritis had caused her joints.
The nurse, well-intentioned as she may have been, assumed that because Eleri is twelve years old, that she could not be chronically ill; especially not with arthritis which is typically thought to be an illness that impacts the senior citizen population. This is an issue that photographer and critic Jerry Thompson touches upon in his work *Truth and Photography*. He asserts that we should not perceive photographs as “an embodiment of some absolute objective record of things as they are, the photograph is a... point of view. It shows things as they appear, not as they ‘are’: different views of the same thing have different effects on the viewer” (Thompson 7). Just as photographs are only one view, and can only present one perspective of a subject, people can only make narrow assumptions about others based on superficial characteristics such as age, gender, and appearance. Thompson’s comment on photographs can further be applied to those who are chronically ill in that “different views” of both people and images can create “different effects on the viewer.” Someone who views a photograph must accept that they are getting a partial truth about a subject, just as anyone who sees a chronically ill individual must accept that there is more to the person’s existence than what they can physically see. To use an example from the project, it might appear to someone who doesn’t know her that Sam is a healthy 24-year-old following her dreams of being an actress in New York City. Based on that one perspective of her, it would be quite easy to assume that is her entire identity. Even photographs of Sam can be deceiving, yet when paired with her narrative it becomes apparent to viewers that there is more to Sam and her diagnosis deeply impacts her daily life. Therefore, it is important to consider Thompson’s words in conjunction with this project, as his insight into photography can be applied not only to the images but the lives of my subjects.
Another photographer who influenced my work was Jim Goldberg, specifically in his contribution to *Hospice: A Photographic Inquiry*. Goldberg is a master at integrating images and text to create complex narratives; one of his signature approaches is asking his subjects to write on the images he makes. With this in mind, I shared my images with each subject and received some interesting comments in response. For instance, Sam was amazed by how swollen her joints looked in the photos, which is something that I was previously unable to notice. In his work for *Hospice*, Goldberg focused on photographing his terminally ill father. He captured the intimate and isolating moments associated with watching a loved one grow ill, weak, and eventually die. Through snapshots, video stills, scanned letters and writing, Goldberg creates a holistic view of his time with his father in the final days, including his time of death. Goldberg includes notes on each day of his stay with his father and often includes observations by the hour. This is a prime example of the need for narrative with photographs, because either side alone leaves many gaps in the story of his father’s death. Goldberg photographed his father at the moment he passed, which by itself is already powerful, but it is enhanced by the note from Goldberg “7:41 A.M. He is dead. My mom is begging me to give him more oxygen. I explain it won’t help. Hospice calls. Someone will be over in thirty minutes. Mom is crying and goes out to get the paper...The house is still warm from the oxygen. Dad is now cold” (Goldberg 48).
The words are as scattered as the photographer’s thoughts must have been in that moment, adding a sense of confusion and almost urgency to the image of his father in his final moment. How does one show something that cannot be seen? This image of his father is Goldberg’s best attempt to document a fleeting, invisible moment: “I could feel something when my father died, but I couldn’t see it. I knew there was nothing I could do to show that moment, other than to literally say, ‘This is it.’ I photographed the time on my watch the instant my dad died” (Goldberg 24). Just as Goldberg had to improvise in order to capture the moment of his father’s passing, I had to create in the moment instead of planning ahead, in order to capture the essence of each person’s struggle. In order to be as authentic as possible in the image making, I tried not to enter photoshoots with preconceived ideas of images I was going to make. Instead,
I listened to the individual stories and had my collaborators show me how they have been impacted by their diagnoses.

Sally Mann was another contributor in Hospice, and adds a unique perspective to the discussion. Mann is known for ethereal black and white images that explore familial relationships, mortality, and decay. She often makes images that abstract commonplace subjects, which is the case for the images in Hospice. In one image Mann uses depth of field to make everything blurry except a white figure that is sprawled out on the bottom left of the photograph. The head of the four-legged creature is somewhat cut off by the frame of the image and I was only able to identify the figure as a dog once I had read the caption that accompanies this group of images:

Windows- What patients see from their windows becomes vital to them. Hospice workers stress the importance of moving patients to allow them a view outside, even if it means a major disruption of the medical set-up. When they look out, the scene is often unprepossessing, the objects in their view random and unaffectioning. The old bucket, the dog sprawled under the eaves, become touchstones, become their very world. (Mann 78)

Mann’s images bring attention to seemingly trivial subjects, such as a sprawled dog, because it represents a much deeper meaning for the bedridden terminal individual. This dynamic in Mann’s images motivated me while documenting objects that could appear trivial out of context. Furthermore, with the exception of one image of her father, Mann photographs objects to represent the people she meets while working on this project. There are no traditional portraits, but in a way the items in her photos function as a portrait of each person.
Another reason Mann’s quote resonates with me is that it reminds me to consider what is meaningful to patients. Someone who is constantly sick, or terminally so in the hospice setting, gains a different perspective on things than someone who is healthy. Placing an ill person next to a window provides them with an escape from their physical confines in the bed or room. Things which are uninteresting or seem “random and unaffecting” to the average person can be powerful to the ill individual. This was especially important for me to consider when working with Eleri who was photographing her surroundings. One specific instance was a photograph she took of a restaurant near the hospital. I passed by the image without giving it much thought, however when I sat down with her and she added context to all of the photographs she had taken I gained a new appreciation for her work. As it turns out, the image of the restaurant was meaningful to her because every time she has a doctor’s appointment at Duke Hospital her mom brings her there to eat and it has therefore become a place of enjoyment and
meaning for her. The patient’s perspective is often quite different from the average healthy person’s view on the same situation or subject. Mann’s approach to storytelling is powerful because she skillfully selects symbols to photograph in place of the disease the patients battle. In this instance, the story is about a man who has terminal cancer but is determined to hunt one more bear before he dies. Mann tells us that the patient shoots the bear and subsequently ends up in a coma. The imagery conjured up by the bear in the story is powerful alone, yet Mann decides to juxtapose the story with a photograph of a stuffed bear (presumably one of the bears the patient had shot.) The angle of the photo makes the viewer feel like they are being attacked by the bear, creating an uneasy feeling that is often present in Mann’s work and particularly relevant to the horrors experienced by the people within the story.

**Untitled, 1996, Sally Mann, “Hospice”**
Documenting Illness with an Ill Body:

While artists like Goldin, Goldberg and Mann create images based on the stories of ill individuals they encounter, it is also worthwhile to consider art created by those who themselves suffer from chronic illness. An artist who was an expert at creating visuals to describe the internal pain that she experienced daily, was Frida Kahlo.

The Broken Column, 1944, Frida Kahlo
While there are many paintings that chronicle Kahlo’s ailments throughout her life, I selected these three paintings because they illustrate her desire to make internal issues externally visible. These examples of Kahlo’s work are centered around her life-long pain and medical complications that resulted from her injuries in a trolley-car accident. The injuries she dealt with
were internal, yet she used these experiences as fuel for her visual work. Painting became an outlet for the sadness and frustration she felt at the loss of functioning within her body. All three images bring use symbols to convey Kahlo’s suffering, perhaps she struggled with verbalizing her experience and was better equipped to communicate with painting. The first image is entitled “The Broken Column” and shows Frida’s body split down the middle with a metal rod, symbolizing the fractures and damage caused by the accident, with nails all over her depicting the pain she felt regularly. The image to the right of that is “Without Hope,” in which Frida shows herself trapped on a bed being force fed. As a result of her injuries and many medical problems she was not eating regularly and had to be put on a food regimen by a doctor. The look on her face is the same in this image as in the other two—a look of consternation and tears. The final image titled “Henry Ford Hospital,” depicts Frida after her miscarriage (which was likely due to her severe pelvic fractures from the car accident.) She painted items of importance to her coming out of her body like babies on umbilical cords, exploring the pain that this tragic moment brought her. These paintings illustrate art’s ability to show the impacts of internal struggles—both emotional and physical—on the human body and psyche. Since Kahlo herself was experiencing the pain herself we, the viewers, gain not only information about her, but a deeper appreciation for the plight of ill people in general.

Two other artists who document their experiences with illness are Mary Kilcoyne and Sarah Bigham. While neither one is a professional artist, their work is still important in understanding the perspectives of chronically ill individuals and how they express themselves. A website called Pulse Voices, specializes in sharing stories of illness with the public in various forms, including paintings and photographs. The first image is a photographed titled
*Juxtaposed*, by Mary Kilcoyne who was diagnosed with stage 3 Hodgkin’s lymphoma in 2014.

She explains the thought behind her photograph:

My sister is the reason I took this photo. She could see how conflicted I was about cancer and chemotherapy, and the realization that my life would never be the same again. One morning she told me to grab my camera, and we walked around our property trading the camera back and forth taking pictures. She wasn’t trying to distract me from everything, but rather to find some way to express it... For me, *Juxtaposed* reflects that there’s never just one side to cancer. There’s the sadness of the diagnosis and the joy of remission— the end of one reality and the beginning of another.

(pulsevoices.com)

Kilcoyne’s photograph has a rich visual contrast and symbolizes the forces of life and death coexisting in harmony. Frank speaks to this harmony: “In modernist thought people are well or sick. Sickness and wellness shift definitively as to which is foreground and which is background at any given moment. In the remission society the foreground and background of sickness and
health constantly shade into each other” (Frank 9). His idea of a “remission society” essentially dictates that people who are chronically ill are neither fully healthy nor fully sick. Just as Kilcoyne’s image shows life and death, the chronically ill individual becomes a space in which health and illness must learn to coexist. Furthermore, Frank notes that “it may not be dying we fear so much, but the diminished self,” (xvi) a concept which is visually represented in the photograph. The juxtaposed imagery that gives the image its title, is that of a healthy, full plant, next to a shriveled, browned plant. Aesthetically the plant is diminished, its function is diminished, and metaphorically Kilcoyne’s body is as diminished as the plant she photographs.

The second image from Pulse Voices, is titled “Medical History, Reimagined” by Sarah Bigham.

This is the caption that accompanies the painting:

‘As a ‘healthcare consumer’ with an artistic bent, I have found it challenging not only to explain my pain to others but to see my health history told in charts, lists, forms and electronic medical records. I have searched for ways to share my story of chronic pain,
one shared by millions of people, in more expressive ways using color and narrative. I created this piece by dissolving supplements (those I take or have taken) as well as medications (those no longer needed) in water and using the resultant mixture to paint on watercolor paper.’ (pulsevoices.com)

Bigham’s creatively uses her medications to tell her story, which is an important step in the reclaiming process. Frank finds that “seriously ill people are wounded not just in body but in voice. They need to become storytellers in order to recover the voices that illness and its treatment often take away” (xx). Bigam views her “health history told in charts, lists, forms and electronic medical records” as a dissociated perspective of her reality, and only through creating a watercolor with the physical medication that is being used to treat her pain, can she accurately explain the pain she is experiencing. Frank also explains that:

Becoming a victim of medicine is a recurring theme in illness stories. The incompetence of individual physicians is sometimes an issue, but more often physicians are understood as fronting a bureaucratic administrative system that colonized the body by making it into its ‘case.’ People feel victimized when decisions about them are made by strangers. (Frank 172)

Bigham uses her artistic abilities to break free from the confines of the bureaucratic system that her illness has placed her in. She cannot be characterized as a ‘case’ in her painting, but she can make use of the tools— the medication— of the “system that colonized” her body. There is an apparent need for ownership in the context of medical experiences, which was a guiding force in my creation of this project. Arthur Frank finds that “an ethic of solidarity and commitment is expressed when the storyteller offers his voice to others, not to speak for them, but to speak
with them as a fellow-sufferer who for whatever reasons of talent or opportunity, has a chance to speak while others do not” (132). These three women—Kahlo, Kilcoyne and Bigham—all experienced life-changing illnesses, but were capable of expressing themselves through art because they possessed the talent to do so. While working with the individuals I photographed, I was able to work from the perspective of an outsider and as someone with an ill body putting me in the unique position of being able to understand both sides. This is certainly not the case for everyone who is diagnosed and it is therefore essential that those with creative abilities share their talents with people who need help expressing their vision; no one should feel unable to share their story because they personally lack artistic experience.

Chronic Illness’ Place in Society:

Much of this paper has considered the desire to share individual stories of illness. However, what happens when there is no place for the story in society? There is a catch-22 in dealing with chronic illness. In my experience we, the chronically ill, do not speak of our illnesses often and instead search for a sense of normalcy. If we express how we feel when we are sick, instead of earning sympathy it can lead to frustration from others who do not understand the severity of our pain. For instance, Kevin stated that part of the reason he does not tell others of his back pain is because when he does, people minimize his experience and say “Oh I have back pain too.” We search for normal days yet others often have no sense of when we are ‘normal,’ i.e. symptom free, or when we are sick. It can be a challenge to verbally explain pain and therefore visuals can be a useful alternative. Overall, working to tell one’s story of illness requires a new way of seeing and sometimes a new way of speaking: “people tell
stories not just to work out their own changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others—each must create his own—but rather to witness the experience of reconstructing one’s own map” (Frank 17). Collectively, chronically ill individuals create a realm in which stories can be shared, and serve as ‘maps’ to navigate the uncharted territory that comes with a life-long diagnosis. I am grateful to have had volunteers willing to share their stories so that others may gain a sense of direction in the face of uncertainty. After all, Frank points out that “the ill body’s articulation in stories is a personal task, but the stories told by the ill are also social. The obvious social aspect of stories is that they are told to someone, whether that other person is immediately present or not” (3). This social aspect is vital in assisting others with a chronic diagnosis, especially because there is a deep-rooted sense of isolation for many chronically ill people. One study that looked at the prevalence of depression in relation to illness found that “patients with chronic medical diseases were nearly three times as likely to get depressed as were healthy controls” (Kang 2). Although it can feel that we are alone in feeling sick on a regular basis we are far from it; in fact in the United States “as of 2012, about half of all adults—117 million people—had one or more chronic health conditions” (CDC 1). So why do we feel alone? I believe it is because there is a lack of avenues for communication between chronically ill people, and very few spaces to speak about chronically ill people in an informed manner. Part of this comes from the stigma that is associated with many illnesses, despite the fact that they impact a large number of people all over the world.
However, this is not a new phenomenon, for centuries fear of the unknown has placed different illnesses and conditions in the spotlight as being dirty. Susan Sontag writes about this in her book *Illness as Metaphor*:

Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious. Thus, a surprising number of people with cancer find themselves being shunned by relatives and friends and are the object of practices of decontamination by members of their household, as if cancer, like TB, were an infectious disease. Contact with someone afflicted with a disease regarded as a mysterious malevolency inevitable feels like a trespass; worse, like the violation of a taboo. (Sontag 6)

Although Sontag’s idea could apply to many other diseases besides TB and cancer, a more contemporary parallel is seen in the perception of individuals with AIDS. In the 1980’s the AIDS epidemic was not understood and therefore terrifying and stigmatized. Today, although it has certainly improved, it is still an illness that has many levels of taboo attached to it. This photograph of Princess Diana shaking hands with a man who has AIDS was shocking to most people because of the fear that he was “morally, if not literally, contagious” (Sontag 6).
Diana was adored by people around the world and she was a humanitarian, yet this moment for many still felt “like the violation of a taboo.” Another example of this connection between contact and stigmatized diseases is the photograph that shows a moment when Pope Francis kissed and embraced a man who many believed to be a leper. Leprosy has historically been viewed as a disease that stemmed from a lack of hygiene. What is even more interesting with the embrace is that the man is actually not a leper, but suffers from a rare genetic disorder that leads to tumors on nerve tissue, visible all over his body.
Regardless of the facts, many people connected him to biblical verses about lepers, including an article in Time Magazine that compared the Pope’s actions with a “story from the Gospel of Matthew: When Jesus had come down from the mountain, great crowds followed him; and there was a leper who came to him and knelt before him, saying, ‘Lord, if you choose, you can make me clean.’ He stretched out his hand and touched him, saying ‘I do choose. Be made clean!’ Immediately his leprosy was cleansed... Matthew 8:1-4” (Time). Even in the Bible there is an association between the leper being dirty and an outcast, repeatedly referring to the fact that he needs to “be made clean” in order to be acceptable. This passage demonstrates the connection between cleanliness (or lack thereof), stigma, and illness have been prevalent for centuries.

People who are chronically ill, and more specifically ill with diseases traditionally viewed as unclean, feel isolated and do not often disclose their diagnosis even today. These limitations extend into daily life for some individuals, including myself and the diagnosis of Irritable Bowel Syndrome.
Syndrome— the name alone conjures up thoughts of dirt and unsavory topics of conversation related to internal organs. As a result, most people do not like to discuss how they feel when they are chronically ill, because they are taught by society not to do so. Many are only willing to speak about it with those who ask and show interest or who are in the same chronically ill community. Arthur Frank cites:

Erving Goffman’s classic work on stigma shows that society demands a considerable level of body control from its members; loss of this control is stigmatizing, and special work is required to manage the lack of control. Stigma, Goffman points out, it embarrassing, not just for the stigmatized person but for those who are confronted with the stigma and have to react to it. Thus the work of the stigmatized person is not only to avoid embarrassing himself by being out of control in situations where control is expected. The person must also avoid embarrassing others, who should be protected from the specter of lost body control. (Frank 31)

This dynamic creates a rift between ‘healthy’ individuals and those in the chronically ill population who might have a disorder that impacts their ability to remain clean in the context of social standards. I often struggle with this unspoken boundary when I am asked questions about my symptoms and diagnosis by others outside of a medical setting. I must walk the tightrope of not embarrassing myself by revealing too much information about my level of body control, while simultaneously ensuring that my audience is saved the embarrassment of having to hear about, or react to, information about my bowels and the stigma connected to an ill body’s functions. One individual who writes about this struggle with stigma, body function and embarrassment is Susan Gubar. Gubar writes about her fight against ovarian cancer in her book
Memoir of a Debulked Woman the term “debulked” referring to the procedure in which they temporarily remove the organs from her body to remove the tumor inside her. She struggles with the idea of dirt and disgust in relation to her body and her diagnosis, and even worries how it will impact her readers, “rubbing a reader’s nose in repugnant body disorders strikes me as a revolting and perverse act…I worry, will these people, the known and the unknown, be embarrassed of or for me since at many moments I am ashamed of myself?” (Gubar xii). I initially mirrored Gubar’s fears with sharing my own story and the details of my illness because of how it might be received by others. However, upon realizing that those feelings stem from arbitrary social constructs I began to feel relieved. Gubar says that despite possibly revolting her readers she shares her story to be a point of connection for others who are struggling with the same diagnosis. This is part of my reasoning for creating this project and sharing my story: if people who are chronically ill speak up and share their stories then others will not feel as alone and that can go a long way to improving the outlook of many individuals. Gubar touches on this in saying that she had looked for other stories when she was diagnosed and that through those stories she connected with “other individuals who have struggled with illness and buoyed me up in the conviction that this sort of witnessing supports numerous volunteers organizing for progress against dread diseases. Reading and writing about cancer cast a lifeline between me and people whose honesty about mortal encounters mitigated my fearful loneliness and thereby steadied me” (Gubar 262). Creating a network of support, even through the written word or images can have a lasting impact, as Gubar experiences from her hospital bed.
Looking Forward:

My project is merely a small contribution to a communication network that needs to be built over time and on a much wider scale in order to make a real impact on the lives of those with chronic illnesses. Arthur Frank notes that “storytelling is less a work of reporting and more a process of discovery” (xvi). All of the artists whose work I explored in this paper embarked on a “process of discovery” either for their own illness or another person’s. Each artist approaches storytelling in a different manner, yet regardless of if the final product is a photograph, a painting or even a website, the important part is that the voices of the chronically ill are being heard. People of all walks of life and diagnoses will need to share their stories in order to bridge the gap between the diagnosis of illness and the life lived after diagnosis. I feel that this project will never truly be complete because there are always more components to add to each individual story, and more people’s stories to tell; perhaps the website could be expanded to encourage more interaction among viewers and include more resources for those attempting to find a sense of balance after a life-altering diagnosis. Hopefully this project, particularly the website component (as it will be more accessible), can serve as a platform for discussion and the telling of stories through any medium.
References


