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The Art of Healing from the Inside Out: A Memoir

Lauren Thelen
Regis University

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THE ART OF HEALING FROM THE INSIDE-OUT
A Memoir

A thesis submitted to

Regis College

The Honors Program

in partial fulfillment of the requirements

for Graduation with Honors

By

Lauren Thelen

Thesis Written by

Lauren Thelen

Approved by

Anandita Mukherji

____Thesis Advisor

Melissa Bosworth

___________   _____________Thesis Reader

Accepted by

Amy L Schreier

______________________________Director, Regis College Honors Program

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ACKNOWLEDGEMENTS

The thought of thanking my family and friends in a minuscule section of a longer work of writing seems like it falls short of what they deserve. Writing an acknowledgements section feels cheesy, I already know if my brothers read this they are going to cringe and laugh. I hope at least some of my sincerity can be internalized and appreciated. I hope we can move past the fact that this does not give them enough thanks or credit. I know that my family and friends deserve my endless thanks and gratitude. If I were to make an attempt to thank them for their greatness in a section of this text, it would go something like this:

To my dad,

I am beyond lucky to have you in my life, you are everything I aspire to be. The way you carry yourself and the way you act towards others are traits I am constantly trying to emulate. You are my rock, my hero, my biggest supporter, my comforter, and my peace. Everyone always asks me what I want to be when I grow up; I want to be like you. You lift me up when I am down, and you hold me close. I will never truly be lost because I have you. Thank you for loving me unconditionally and pulling me out of this darkness. I love you.

To my mom,

You are the best of the best. You are kindness, love and light personified. Being your daughter, and being told I am like you brings me so much joy. I can only hope to come close to the amazing person, friend, daughter, and mom you are. I never feel alone, because you are always there for me when things are good or bad. You are a constant in my life that I will never take for granted. I love you.

To my siblings,

I sometimes forget how lucky I am to have three of my favorite people as built-in best friends. We laugh together, cry together and support each other always. Thank you for holding me up when I was struggling. I love you guys.

To Dr. Narcisi,

Thank you for not letting me drop out of the Honors Program. I was flooded with doubts and intense imposter syndrome, you helped block out the negativity and encourage me to not give up. I firmly believe that this thesis is complete because of you.

To my advisor and reader,

Thank you for the countless hours you spent discussing this project with me and thank you for all of the feedback you provided me with. This project would not have been the same without you.

To Kaitlin, Katie and Bella,

Thank you for being my best friends. I am lucky to know you, I have honors to thank for that. Proud of you guys, always.

To everyone else that supported me, prayed for me, or was thinking about me, thank you.

ABSTRACT

Name: Lauren Thelen Major: Health Care Administration

The Art of Healing from the Inside-Out: A Memoir

Advisor's Name: Anandita Mukherji, Ph.D.

Reader's Name: Melissa Bosworth, MS

The health care system is no stranger to many of us. From before we are born to our last days, we interact with health care settings and providers. This is a good thing--we receive care and feel better--or at least that is the case most of the time. What this statement does not acknowledge is that the health care system fails us, through inadequate communication, dialect barriers and inability to diagnose. The purpose of this thesis is to expose how harmful these issues can truly be. Having experienced the effects of poor communication and medical jargon, I can attest to how difficult the health care system can make communication and understanding. But I do not expect the reader to just take my word for this. I utilize research to expose the issues in the health care system that I experienced firsthand. I dug through my memory to relive and share my health struggles and then honed in on the issues in the health care system that set me further back and researched what is leading to these issues. The purpose of this thesis is not to fix the health care system overnight; it is deeply broken, and it will take time to do this. The intent is for this to be a step towards making it better by opening the eyes of people and patients so they can advocate for themselves and maximize on the face-to-face time they are granted with health care providers. For me, the purpose of this thesis is to heal from my past and to remind myself of my passion for improving the health care system as I enter into a career in health care administration.

Trigger Warning: this thesis will be addressing topics about and related to body image, eating disorders, mental health, and negative self-talk.

CHAPTER 1: BEFORE

Usually, people visit the doctor once a year or so for a routine checkup. They feel pretty good but want to make sure everything is ok, and they are up to date on vaccines. I, on the other hand, was seeing doctors at least once a month. Sometimes it was the same doctor, often it was a new doctor. I sifted through the doctors specializing in gastrointestinal health across Nebraska and Colorado. I saw 10 doctors during my teenage years, and I left their offices feeling crazy and discouraged.

Most people experience fluctuations in the way their body looks and feels as they become the adult version of themselves. For me, I hit a standstill around the age of 14. I was barely in high school, and I noticed I was not growing anymore. At the time, I felt like I looked good, but looking back, oh my gosh, I was so sick: skin and bones. I remember the day that everything came crashing down, the day my family left for vacation in the Ozarks. Just my luck that my sickness would erupt on vacation. As someone who loves to swim and be around family, I should have been so happy. What should have been a fun-filled trip, full of memory-making and endless time outside, instead turned into never ending alone time. I was alone in the bedroom making frequent trips to the bathroom to throw up. It was miserable.

Nothing helped, and my parents were caught between making vacation enjoyable for my siblings and worrying about me. They got me my favorite snacks to see if I would eat, but I could not keep anything down. I was presented with Bite Sized Tostitos chips, Twix bars, and strawberry Pop Tarts. None of that sounded good until the drive home. I was fully consumed by pain for the days of vacation. But for a moment on the drive home, I wanted something to eat. I wanted the Twix bar; I needed the Twix bar. My grandma went looking in the snack bag. Unfortunately, the snack bag was crammed into the trunk. My grandma dove into the back of the car, making it seem easy despite her age. She dug through our ridiculous and unnecessary amount of snacks for my siblings and me. No Twix bar to be found. In that moment, I remember believing that it was lost. Looking back, one of my brothers likely ate it and did not have the heart to tell me. They looked at me with such sadness and sympathy, but no one could make it better.

I lost more weight during this vacation, weight I could not afford to lose, and looked ghostly. I forced myself to go out on the boat with my family and the only thing that gave me a moment of peace was to do a polar plunge into the freezing cold lake. When I was underwater, my chronic pain would be drowned out by the shock of the cold water wrapping around my body. The way a blanket protects you from the cold, the water protected me from the pain. Cold water normally feels painful, it shocks your bones. It had the opposite effect on me. During this time, it almost felt pleasant in comparison to my other pain. The shock of the water was comforting, predictable, expected. It surrounded me and tickled my nerves and prevented them from registering the pain brewing elsewhere in my body. Outside of that brief moment, I was in excruciating pain and a constant state of nausea. I did not always feel great before this trip, my stomach would hurt or be upset more frequently than others. What was different was the curl-myself-over pain that lingered and then struck me harder. I was not prepared for that. How could I have been?

From that vacation forward, it felt like I was stuck in a revolving door seeing doctors and leaving with no answers. This repeated event was draining. How am I supposed to feel when some of the most educated people around cannot seem to make sense of this situation? I felt helpless and my remaining hope was dwindling down fast. One doctor put me on medication she said to take every day “for the rest of your life.” At 14, that felt like I was signing my life away, I was no longer in control, this medication dictated my life. This did not sit right with me, or my parents. So, my parents never stopped searching for answers. My mom was my number one advocate, searching for answers when they were nowhere to be found. The search for answers was long.

This miserable state went on for five years. I saw a few doctors, but they told me that I was fine, even when I was in pain. I was hospitalized a handful of times but was always discharged with no answers and bottles of prescriptions. My parents were not satisfied with this type of treatment and thank God for that. They kept advocating for me and pushing for better care. I learned to live with the pain and looming nausea. Most days I could suffer through class and push through time with friends. But I was a zombie. I was not living. I was just getting by.

In high school, I was sitting in Physical Science class, right at the start of the day, feeling as good as I could be while being this sick. And then we started completing a few worksheets and I was hit with pain and pressing nausea. I rushed to the front of class to tell my teacher that I had to leave class, he knew that I was pretty sick and gave me a comforting nod. I rapidly shuffled out of the classroom and made my usual trek to the nearby bathrooms; except I was too late. I found one of the hallway trashcans to throw up. It was quick, and I don’t think anyone saw me. But I was so embarrassed, but I knew that this was my life, I had to be ok with that. I marched to the bathroom, head down. I washed my hands, splashed some cold water on my face and my neck and popped a piece of gum in my mouth before dragging my feet back to class. I kept gum in my pocket for occasions like this, conditioned to live with the frequent trips to the bathroom to throw up. My teacher was happy to see I was back in class, he always told me I was one of his brightest students. If only he knew how much of a chore it was for me to be in class and still perform well. My whole life was a performance during this time. Put on a face, act like I am fine, do not show weakness. *But I was weak*.

CHAPTER 2: DISCLAIMER AND WRITING PROCESS

Body image and views of oneself go deep into one's mind and are difficult to push back on. It can feel like a deep pit; hopelessness and insecurity are trademarks of this negativity. It leads to skipping meals, negative self-talk, and dark thoughts (Gay, 2017). Roxanne Gay, and many others who have embarked on a memoir writing journey, will guide my work. This is not a task that I take lightly; as Gay herself claims that “this was the hardest thing to write” (Gay, 2017). I want to be ready to face that challenge head on and learn from myself, from the others around me, and those who have come before me.

Writing a memoir is like unraveling aspects of your life and mind; this form of writing is deeply personal and transformative (Rentzenbrink, 2022). I fear that, in writing this, my sense of reality will get muddled and I’ll go back to being deeply confused by my feelings. I have been having dreams about this thesis consistently during the writing process. My first dream was that I wrote this memoir, that I told my story and felt peace. Thomas Larson, author of *The Memoir and the Memoirist*, says that is how the writing process should feel. I also inspired others through my writing and felt accomplished as a result. In a similar vein, I have been having dreams that I will fail at writing this, will not do my story justice, will not help anyone, and will fall back into my confused and complicated habits. That scares me. Thus far, my mind has been stronger than its confused thoughts, but the fear is omnipresent. The looming “what ifs” have been keeping me up at night. What if I am not actually better? What if it is all a façade? What if no one ever truly heals from something like that? What if I do this all for nothing? My hope is that this work will be a synthesis of personal expression and commentary on trusted sources to help me and my readers better understand how to manage the health issues that they face and how to navigate the health care system.

During these thoughts, I find myself turning to music as a form of therapy. And let us be 100% honest here, I find myself turning to Taylor Swift. She is inspiring musically and gives me a safe space full of lyrical and musical genius. She also gives me comfort as she faced similar struggles to me but did it in the public eye (Miss Americana). She fought negative thoughts about her body image and eating habits (Willman, 2020). While her experience was being plagued by an eating disorder, I was battling medically induced struggles with eating. One mentally focused, one physically focused, both paralyzing struggles. I cannot imagine going through this experience and having even more criticism than I did. Comparatively, I do not have the following that Taylor Swift has; I am not in the public eye. The number of people I faced judgement from is not even close to the same level that Taylor Swift did. That does not devalue what I went through; life's challenges and trauma should not be taken lightly or compared, as we are all unique and so are our struggles. We must not engage in reductionism. That being said, it gives me hope that someone like Swift, who experienced these struggles in the public eye, and who experienced criticism at every turn, could face this and get better, no matter how challenging.

This story boils down my whole life into this time span of a few years. They were significant and formative but that is not all there is to me. I have lived such a beautiful, amazing, privileged life with a wonderful family. Everyone faces hardships, and I do not want to be defined by mine. I want to be seen for more than just my struggles. I want to talk about anything other than being in the hospital and being sick. It is hard to picture a lot of things during that time of my life which proved to be a challenge in writing. I am so far removed from this experience, but it is a part of me and a part of my story. Emphasis on “a part.” I am more than my struggles and I am grateful for the life I have lived and how it has shaped me.

For this work of writing, I am attempting to synthesize a few parts of my life, a few parts of my brain, a few moments in time. I have leapt joyfully into the realm of creative writing and found a home there. I find that the words that tell my story matter. So, I highlight some of my story through lyrical, elegant writing. The work starts with sharing about what life was like before I realized I was sick and had to get surgery. It helps create shocking juxtaposition of what life was like and what it would become. From there, I share with the reader what my methods and processes were when writing and I am honest about what will be addressed in the text. Before jumping into all of the details and complexity, I focused the following chapter on simplifying many years of my life and all of the surgeries I endured. I then skip to a jarring use of the creative writing form called braiding. I weave together my inner thoughts with the visceral moments of my family dinner routine. I contrast those with one another while maintaining elements of mystery to keep the reader guessing like I was. I followed that with a brief section on commentary from others and how it impacted my view of myself. From that section, I move the reader through my health care struggles and treatments, both creatively and analytically writing to give context and a well-rounded picture. I thought the treatments were as important as the healing process, so Chapters 6 and 7 reflect that. After that, I turn to research to prove that my health care experience was not a stand-alone case. The health care issues are very present and very real. And lastly, I draw conclusions about myself and the state of the health care system. The structure of this thesis flows through creative writing, reliving my past, research to understand and hopes for the future. It moves through topics in the same way my brain jumps to new thoughts and ideas. I have always been caught between my love for art and creativity and my health care passion. This thesis allows for me to do both justice, to walk the tight rope so delicately, in order to make both parts of me happy and proud. But I think that makes it uniquely mine, and I am excited (and equally terrified) for it to become uniquely yours.

CHAPTER 3: PUTTING IT SIMPLY

During my first year of college, my mom heard of a doctor who specialized in stomach issues and surgery for children. I got an appointment but highly doubted his ability, considering my track record with bad doctors and nurses. I had little to no hope, so this felt like just another brief stop on the revolving door of doctors. But nevertheless, I met with him and was very impressed. I remember phrases like "I know what is happening" and "I can fix this" flying around the room. I had my doubts, but he proved me wrong time and time again. I had three surgeries following that initial appointment with my doctor:

1) Noninvasive endoscopy (scope) to see if he truly had identified the issue.

Translation: they put me to sleep, put a camera down my throat, and identified a narrowing in my intestines that was causing my pain, my struggles with eating, and my inability to gain weight.

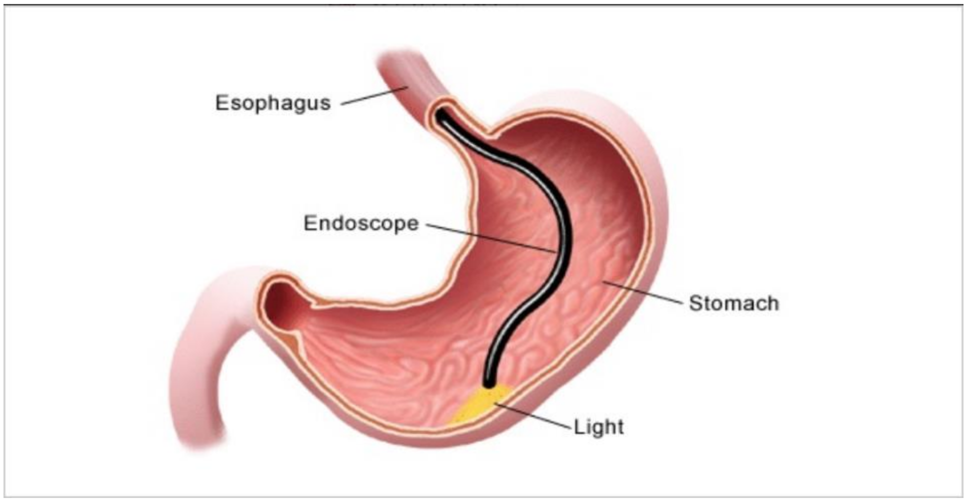

Figure 1- Noninvasive endoscopy (Stanford Medicine)

2) An initial attempt to widen the narrowing through the placement of a stent. That ultimately failed because it was so narrow, and the stretching caused pain.

Translation: They put a device the worked like a Chinese finger trap in the small part of the intestines. The Chinese finger trap was much, much wider than my intestine and the pain was intense. So, the simple fix had failed.

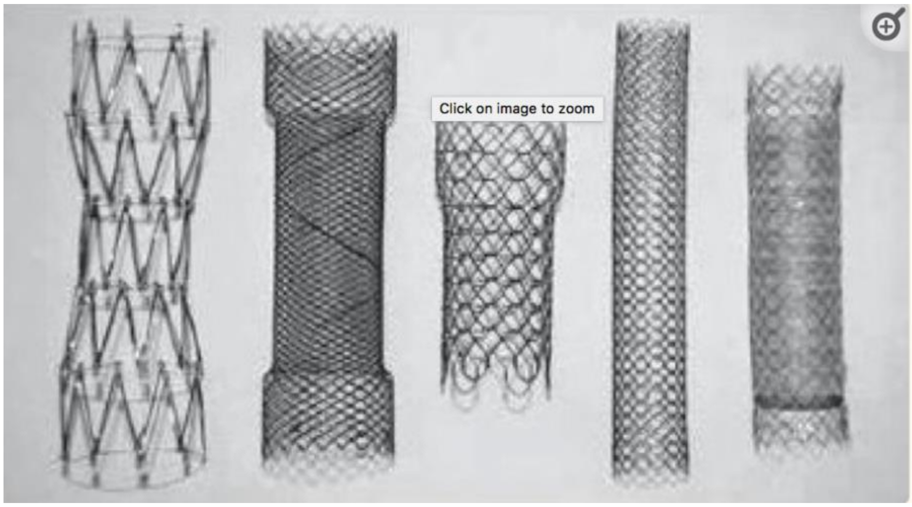

Figure 2- Stent or Chinese Finger Trap (National Library of Medicine)

3) The final surgery that fixed everything: a laparoscopic gastrojejunostomy duodenal bypass.

Translation: the doctors and surgeons used robots to cut in my intestines and reattach it above the narrowing. When I joke about this time of my life, I say they sliced and diced up my intestines and put it back together like a puzzle, just removing the piece that did not fit. The narrowing in my intestines was like a piece from a different puzzle that got mixed up in the wrong box. This surgery completely bypassed the problem and I have no issues with that area of my health anymore.

Figure 3- Laparoscopic Surgery (NS Medical Devices)

Surgery 1

I was used to getting put to sleep at this point. That is what the doctors do when things are serious or painful. Today was no different. But it was relatively quick. For my parents, they were away from me for about 45 minutes. For me, I was away from them for five seconds. This was not really a surgery, that is why the doctors throw out the term “noninvasive” in front of “surgery.” This just means there was no cuts or openings made to my body. From what they tell me, they carefully put a little camera down my throat and the camera just ran into a road block. This road block was the narrowing they thought I had. They confirmed it and we moved to stage two. Or Surgery 2.

Surgery 2

I lie in bed and hope for sleep at night. But when I go to the hospital, a false version of sleep finds me instantly. The nurse gives me an IV and I am out in a few seconds. That is not real sleep, you always wake up more tired but also rested. It is fuzzy and weird. Not like I woke up on the wrong side of the bed. It is a cloudier feeling than that. Hope bounced around my mind as the medication guided sleep towards me. Pain flooded my brain when I woke. How could the pain have gotten worse? Screams echoed in my head, but I did not speak. I searched for my mom in the blurry room. As I was asleep, the doctors placed a “Chinese finger trap” in my intestines. The stretching was excruciating. My skin turned red like my blood was boiling, it very well could have been because of my frustrations towards the doctors and surgeons. I avoid using the word hate because it is so harsh but gosh, I hated them. My mom was patient and kind, she saw my frustrations and calmed me with a hug.

They sent me home. In pain. That was the norm, I started to believe the doctors got some twisted enjoyment from doing that. From only doing their job halfway and causing more pain for me.

The health struggle that plagued me for five years was fixed in 14 days. Time is both freeing and constricting. My life was defined by my health struggles, then by my surgery, then by the healing, and now I want to be the one to define it from here on out. I want to be free of the weight I have been carrying and allow myself to move forward. I want to move forward having this lived experience shaping some aspects of who I am but no longer manifesting itself in the form of a dark cloud over my head. Rather as a faint memory of who I was that guides who I wish to become.

Surgery 3

This is when they fixed me. I felt better. I felt good. This was considered minimally invasive. I didn’t like that wording. It made me feel like I was not allowed to struggle in recovery. My recovery was much less than open stomach surgery. But I still experienced pain, reduced ability to function and difficulty feeling better after the fact. They told me the scarring would be minimal but I also know they will be a part of my body forever. The point is, minimally invasive surgery is still taxing on your body.

Prior to the surgery, the nurse came in and the IV was placed. Things started to fade to darkness and I do not remember what happened for the next couple of hours. From what the doctors and my parents tell me, I was cut in three places on my abdomen. To the right, the left and directly below my belly button. On the right side, they placed the light and camera so the surgeon could see what he was doing. From the left mostly, and the middle occasionally, the robot arms were able to cut my duodenum and rearrange a small area of my intestines so food could smoothly pass through.

The process of regaining consciousness seems simple. Your brain wakes up and you open your eyes. Simple, two little steps. That is how it went when I woke up in the hospital. I was disoriented and wanted to see my parents right away. I wanted and needed that comfort, that peace of mind. I may have been 19 years old at the time, but I needed my mom and dad with the desperation of a child.

Well, that is one of the things I needed. The other was apple juice. In my mind I was whining and yelling to the nurses to get me apple juice, but the anesthesia wearing off likely inhibited my ability to shock the nurses into bringing me the hospital apple juice. I have had a lot of apple juice in my time, but when it comes to you in a cup with a lid like Jell-o or pudding, and you get to poke a straw through it, it truly does not get any better than that. The apple juice came into my room, with my parents and some nurses. I was on the other side of this journey; I could feel it, like how you feel the air change from summer to fall. One day, everything feels different. For people that love fall, that is a good different. For people that prefer summer, they mourn the loss of their favorite season. Time will tell how I feel about this change in my life.

The process of waking up from the dark clouded daze I found myself in was not simple. It was grueling and taxing on my mind and body. I would get glimpses of clarity. Moments where I would feel good and at ease. Where food was my friend, not my biggest opponent. Where I used the gym to feel strong, not to feel pretty. Those moments were few and far between. Part of me wondered if it would have been easier to remain stuck in the storm, without moments of sunshine and rainbows. Looking back, that is not what would have been best for me. It was those moments where I would question the habits that I had fallen captive to. I would question whether my relationship with food was normal, or whether it was walking the line between healthy and unhealthy, safe and dangerous. That is a very fine line. I walk this line very frequently; I am learning that I am good at balancing. It takes me back to the balance beam that I would go on during recess in elementary school. To maintain balance, I had to be slow, calm, confident, and focused.

Waking up physically was quick. One moment and the action was done. I was alert and I was awake. Following that moment, however, I was mentally asleep for almost a year. The daze consumed me, but I was unaware. I was just going through the motions, letting my thoughts control me. I went round and round in this unhealthy, seemingly never-ending cycle.

CHAPTER 4: ANXIOUS AND HIDING

In my head

The sparkling sun and glistening water surrounded our home away from home this week. At least that was what I was told by my family members that were able to enjoy the vacation we were on in the Ozarks. However, contrary to what the setting would make you believe, I was not at peace. My reality during that time was confined to four bathroom walls and a toilet. Life was less than magical. I was lonely, sick, and scared. I went from being a fun, healthy and capable human being to a ball of pain. This shift was likely gradual and then all at once, but at the time it felt like it came out of left field, like the shift happened in mere hours. So unexpected. I remember very little from this trip. I remember being fine on the drive down and then spontaneously unwell, something that I could not get rid of from that day forward. The pain, the vomiting and the hospital trips only increased in frequency.

...

For most of my life, my bed and I had been two separate entities. I would meet up with my bed to sleep, and I would effortlessly get out of bed to go about my day. That was no longer true after that family vacation. I no longer possessed the strength to rip myself from the hold of my sheets. The pain engulfed every part of me. So, I laid in bed and memorized the look of the ceiling. The grooves and ridges, the way it met the wall. I studied every little imperfection until I fell asleep and was granted a few moments of peace. That peace was shattered at all hours of the night. Finding comfort in the midst of absolute discomfort was proving to be as impossible as it sounds. I would open my eyes when the pain struck, and I would sit up in bed. I was learning how to find a position that caused the least amount of discomfort. That involved me grabbing my pillow and placing it in my lap as I sat crisscross applesauce. I would put my face in the pillow and hope for sleep to come.

Family dinner

“Dinner is almost ready,” my dad announced. I knew the table needed to be set, it was my turn tonight. Six plates, six forks, six spoons, six knives, six napkins. My brother was in charge of getting people what they wanted to drink tonight. I wanted milk. I carefully placed the plates and silverware in their places and waited for my family to take their places; we have unassigned assigned seats. Dinner feels off if we are out of place.

In my head

After a year of enduring pain, I studied the imperfections and intricacies of the ceiling in my bedroom for hours on end, as I lay in bed with no answer in sight from doctors who were supposed to help me. I was studying what I liked and what I did not like about it. I became really good at this; I noticed how good I was at tearing things apart when I looked in the mirror in silence and tears began to stream down my face. My eyes roamed every part of my body and failed to find one thing I did not hate. I was far from perfect, and I knew exactly where I fell short. Other people’s words about the way I looked and how I had changed flooded my brain. Their comments had corrupted my comments about myself. As much as I hated the way that I looked in moments like this, I hated the people who said things to me first.

Family dinner

Taco night is my favorite. I could eat dozens of tacos and end up in a food coma and be so content. My dad makes the best tacos. We had the whole table covered in food: tortillas, taco meat, cheese, lettuce, salsa, guacamole. Taco night *was* my favorite. We prayed and we started to eat. We were laughing, it was happy. I screeched my chair backwards and started making a run for the bathroom.

In my head

Before and after the surgery, I felt a shift in how I viewed myself. I was weak before and now I feel stronger and healthier. That was a liberating feeling. Until others took note of how my appearance shifted and they were so vocal about it. My body was growing in the way it was supposed to, gaining strength in the way it was supposed to. So, I was left to wonder why people thought they were supposed to comment on how I looked.

Family dinner

Senior year of college. Crying in the library contemplating whether or not to eat. That is what my Wednesday has become this week. Nothing sounds good. Dinner means family and my family is not here. That is leaving space for my mind to tell me not to eat. It is all consuming. It is loud. It is hard to fight it tonight. It hasn’t been like this in a while. Am I ok? It is not that I do not want to eat, gosh I love food. But it hasn’t always loved me. I found it easy to skip meals on occasion out of habit, I couldn’t eat a lot while I was sick. I am still adjusting. Food is scary. Food is not my friend. *Screw this, I am getting Chick-fil-a.*

I spiral sometimes. Ok, frequently. God, ok fine! More than normal. I am so consumed by the thoughts running laps in my brain that I lose track of time. I think that is what I am going to chalk that last section up to. I was spiraling. Well, maybe reliving a spiral. My life felt so discombobulated and disconnected. I was so out of touch, yet so abundantly aware of the lack of normalcy surrounding me. Life was like "driving a new Maserati down a dead end street, faster than the wind, passionate as sin, ending so suddenly" ("Red," Taylor Swift). I felt moments of bliss, of peace, of some sense of normal. Only to be jolted back to my reality by the seat belt catching my body from flying in the car, knocking the air out of me and reminding me of what my normal was. *Pain*.

I was consumed by this throughout high school and early college. That is already a trying time for people. On top of normal issues like boys, acne, awkwardness, I was silently coping with shock waves of pain consuming my existence. I forgot who I was before the pain.

CHAPTER 5: UNWELCOME COMMENTARY

Pre-Surgery Praise

“You are so pretty”

“Oh my gosh, you look like a model”

“Rate: 10/10”

“What is your workout routine”

“Will you model for us”

“Rate: BMS”

Post Surgery Hate

“You look heavier”

“Rate: 4”

“What have you been eating”

“You are a lot rounder in the face”

“Rate: 6”

“What is going on with you and your body”

Imagine being praised for being sick and being made fun of for getting better. How was I supposed to feel good about getting better when I was getting hated on for it?

When others pointed out that my body and appearance had changed, I took it hard. My self-esteem was shot, the reflection I saw in the mirror was distorted and the negative self-talk increased at a rapid rate. I constantly heard the words “ugly,” “fat,” “out of shape” move around in my head. They played ping pong within the constraints of my brain. For inaudible words and sounds, it was deafening.

During my health struggles, I did not gain weight all throughout high school; I was 110 pounds and very unhealthy looking. But it was during that time that people told me “Gosh you are beautiful,” “you have the perfect body,” and “you should be a model.” Those comments were less frequent when I put on weight, following my surgery at the beginning of my college career. Before I gained the weight I needed to, I would get lightheaded just from standing, and felt weak, like a twig ready to snap off a tree.

But why was my sick and unhealthy body praised? I acknowledge that shaming me for it, saying I look sick or unhealthy, would also not be great, but that raises the question of why the hell do people comment on the bodies of women and girls anyway? We compare, we judge, we praise, and we comment. Why don’t we just shut up? It is not our place. You never know what someone is going through. It is unkind and unfair. Even if the comment is meant as a compliment, it can be skewed and misinterpreted. For example, if you tell a girl she looks pretty and she is wearing a full face of makeup, she now might associate her beauty with wearing makeup. This is not the type of environment we should foster.

After the post-surgery weight gain, I turned to the gym, but not in a healthy way. I sought instant results that would lead to a thinner, “prettier” body. I wanted the body that I had lost, the body that people praised. I worked out aggressively and consistently. But I felt no gratification from myself; it only made me feel worse. I started putting on muscle which led to higher numbers on the scale, and I could not handle that. I took a step back and realized what I was doing to myself, what I was doing for the approval and praise from other people. I took time off from the gym, forced the negative motivation behind my relationship with the gym out of my head, and I healed from that. That sentence makes it seem simple. It was a constant back and forth struggle to love my new body. The body that is strong and healthy. I studied every part of my body and found something I love about it. What is interesting is that I realized what I love about my stomach is my scars. I think of Taylor Swift saying, “you drew stars around my scars” and that is what I want to do: make my scars beautiful (Swift). The scars are proof that I am doing better.

I have since returned to the gym and have fallen in love with it. This time, however, my passion does not stem from a desire to attain the beauty standard for my body, but instead from the desire to gain strength and feel good in my skin. There is a way for the gym to be healthy and make you feel good. Throughout my healing process, I have learned how to change my perspective on the gym and since then, I make the effort to hold tight to that mindset.

CHAPTER 6: FROM THE INSIDE-OUT

I did not love high school, but I also did not hate it. I feel mostly indifferent about that time in my life. I remember feeling pretty and getting a lot of praise about that from the popular girls, and that felt nice. I would weigh myself on the scale from time to time and see two ones and a zero: 110lbs. Every single time, no fluctuations. I felt lightheaded somedays but just kind of accepted that as part of life. I thought it was normal.

I turned 16 and quickly realized my perception of reality and seeing my state as “normal” was skewed. Family vacation that year turned into my own personal hell. I was spontaneously sick. Constantly in the bathroom. Constantly throwing up. What I would later learn is that this was the result of a narrowing in my intestines. This was likely something I was born with but was not aware of until I started to grow. I was fine until I no longer was. I later learned, this is called a congenital condition. I was born with it but did not face any repercussions until later in life.

I reached a point on my family vacation when I could not keep down food. I loved food and continued to indulge in the foods that made me happy: pasta, tacos, sandwiches, burgers. My stomach and intestines would try and try to digest the food that I loved so much. But it simply could not. I would be left curled over for hours on end trying to find a moment of peace. My stomach would slosh around until it could not bear to try to digest my food a moment longer. That led me to run to the bathroom. The food came back up and the cycle began again. Eat, vomit, repeat. It was not sustainable, and it was not by choice, but it was my life. The numbers on the scale began to plummet, a one, a zero and a two, a nine and a seven, a nine and a zero. I had never felt weaker. The praise I was receiving before became more frequent, it would give me a moment of happiness. It felt good to be called “pretty” and “a model.” Who does not want to hear those words? The happiness only lasted briefly. Then I was snapped back to my reality of pain and discomfort. A constant state of having an upset stomach.

I am numb to having an upset stomach and vomiting. That is what five years of that will do to a girl. It was all I knew. My parents saw this happening, it did not go on for five years unaddressed. They tried, without fail, to make it better. I felt like the doctor's office was a revolving door. In and out, leaving more disappointment within me each time. I was confused by how medical professionals, who study for twelve years at a collegiate and graduate level, could fail time and time again at their job. One doctor told me nothing was wrong with me. One doctor told me my body produced too much acid. One doctor told me I needed to be on medication for my whole life (I later found out that if I had taken said medication for five years, my bones would have disintegrated. Who needs bones anyway?). One after another, I was made to feel like I was crazy. Like the intense pain and never-ending nausea was all in my head. Like my feelings weren't real. Like I was making it up. I wish I was making it up. I wish I never felt like this. The struggles made the relief I felt when I reached the other side that much more rewarding.

During the time I was sick, I craved answers so deeply. We are supposed to be ok with the not knowing, right? We are not meant to know everything. But I craved answers. My whole body ached for answers, or maybe it just ached. But gosh, I needed to know. I am like any other person, I use Doctor Google and even diagnosed myself with an eating disorder as a teenager. How could I not? I felt like all signs were pointing me to that diagnosis. I craved a diagnosis so badly that I jumped to the most convenient one. I need to work on that. Not jumping to conclusions would save my sanity in many other situations. But that is not the point. I did it anyway. Doctor Google felt like the closest thing I could get to a doctor caring about what was going on. It would look at all the symptoms and reach a few conclusions. I liked that better than what the doctors were giving me, but it still felt wrong. Doctor Google told me I had an eating disorder, it also told me I had stomach cancer, and it told me I was hours away from death. So, clearly Doctor Google was wrong because I am here writing this story, alive and well years later.

The alarm clock illuminated the time: 2am, and the frantic scrambling amidst pain began. My phone had made its way to the floor, I needed it. I liked to imagine a little doctor's coat around my phone, that made the role my phone played in my life more justifiable and comprehensible. My phone was my doctor. Google was my doctor. My tired eyes squinted at the bright light on the screen. Google was already pulled up when my phone unlocked. This time was not a standalone case, it was an almost nightly occurrence. All of my symptoms were entered into the little search box on my shockingly bright screen. I paused to turn down the brightness, it was making my head hurt. Search: nausea, vomiting, abdominal cramping, back pain. Would it be a bad idea to type that I felt like an alien was trapped in my stomach, it moved around aggressively like there was something nonhuman in there. Ok Doctor Google, tell me what is wrong.

“Oh, dear Lauren, you seem to be really struggling. And I hate to heighten your stress, but it is important for me to share that this is a very serious, life-threatening situation. After thorough consideration, it looks like you are dying or pregnant. No other possibilities.”

I pleaded and explained that there was a 0% chance of me being pregnant. So that meant I was dying. I crawled out of the doctor’s office, or my bed, whatever you want to call it, and went to cry to my parents like a child.

I wept and told them I was dying. Looking back, I feel so bad that I startled them awake and with such terrifying assumptions about my state of health. But I was left to my own devices, literally, and I did what any normal person would do: search for answers.

In December 2020, I went home for winter break during my freshman year of college. I learned my family would be moving from Colorado to Michigan. I also saw a doctor and was scheduled to have surgery in February. The doctors thought why not make me wait a little longer to feel better. I think part of the reason I am spending so much time discussing my own life is because I still wrestle with the fact that I never got a clear diagnosis. What I do know is that I had a narrowing in my intestines which led to discomfort, pain, nausea, vomiting. They think I was born with it, but they never found out for sure. All I do know is that they fixed the problem. But I am still left without answers. This does not contradict the fact that my final doctor was kind, he was patient, and he listened to me. He was the first doctor who saw me as more than a checkbox on his to do list. He actually gave me the time of day. I remember hearing him say he knew what was wrong and he knew how to fix it. A weight lifted off of me and my parents. He told me that it was time for me to no longer feel sick. He made me feel seen. He was going to make the pain and nausea go away. I spent five years chasing this feeling of relief, and he was going to give me that.

In February 2021, I had scheduled surgery. My care plan was going to be addressed in waves. Wave one was placing a stent. My intestines were narrowed at the upper part. It would make sense to stretch it out. In theory, my problem could have been fixed in a non-invasive surgery. I went in, got put to sleep and woke up in more pain. I was shocked, I was angry, I felt defeated. *Was I a lost cause?*

The reason for the doctors addressing my treatment in waves is likely twofold. The doctor likely wanted to do the least invasive surgery first to lower the risks and avoid extensive recovery time. Additionally, laparoscopic surgery carried more risk and the hospital likely worried about the liability involved. The liability claims and potential financial loss at stake often drive medical decisions. I appreciate the attempt to fix my health issues in a simpler way, but I experienced great frustrations as a result of the extra hospital visits.

I was discharged from the hospital the same day as the stent placement; I went home and had a follow up Zoom call with the surgeon who was supposed to help me. I cried, I screamed, I was in pain. He calmed me down and assured me that he would fix it. He said the narrowing was smaller than he thought. He said he understood that I was in pain, and he would make it better.

I went back the next day, and they removed the stent. I felt a little relief then, but the anxiety began to hit me. The simple surgery had failed me, it did not fix it. That meant I had to get the scary, invasive surgery. I watched this realization hit my parents like a wave on a red flag day at Lake Michigan. It hits hard, knocks the air out of your lungs and plows you over.

Ten days later, I was scheduled for the big surgery. The real deal. At least it was a quick turnaround, right? I did not sleep the night before. I was going over what my doctor and surgeon had told me earlier that day:

> "I am going to make three small incisions in your lower abdomen. I will use robot arms to move through the incisions to find the narrowing we know is present in your duodenum. We will bypass the narrowing to allow for a wider opening your intestines."

I hated how formally he spoke to me. Doctors are not granted enough time to communicate with patients in a manner that makes sense. They are backed into a corner and forced to communicate quickly and formally. Clearly, these methods are not working. I tried for hours to make sense of what he said. It prevented sleep from finding me. I wouldn't have gotten more than five hours of sleep anyway. I was on my way to the hospital by 5:45am. My dad drove me, my mom had to take care of my other siblings and would meet there when I woke up.

My dad is in tune with others' emotions. He sensed I was on the precipice of my biggest breakdown to date. He looked at me and saw the flood gates were about to break. In the same second, he started blasting music in the car. "Seven Nation Army" by the White Stripes on repeat, the whole way there.

"Bun Bun, a seven-nation army can't take you down!" My dad yelled over the music.

We danced, laughed, and cried. We were both terrified of what was to come. But my dad gave me a few moments of bliss with him. He knew what I needed. Moooooo do do do do dooooo do. The sounds echoed in the car. My dad played air guitar. We both bopped our heads to the beat. We pulled into the hospital parking lot. Five minutes early. My dad was good at that, we were always on time or early when he took us places. We hopped out of the car and marched towards the gliding automatic doors. My dad said, "It's game time."

We were filed into the hospital, it felt like we were being herded. Right to the counter, right to the uncomfortable, scratchy waiting room chairs. Then the waiting began. In reality, it was mere minutes. In my mind, it went on for hours. A door swung open, and a voice called out, "Lauren."

That was my cue. Time to take the stage. I followed her, and quickly looked behind me to ensure that my dad was close behind. He was. He always was. I was led into a room with a glass sliding door, a curtain, a typical hospital bed and the IV cart that I would be hooked up to shortly.

I tied up the hospital gown, which is a fashion crime, and was told I needed to remove my earrings *and* nail polish. While it may seem dumb, having my nails painted and all of my earrings in just makes me feel like *me*. I paint my own nails after deeply contemplating the color for the week. And I fill the excessive number of holes in my ears with perfectly picked earrings that match my outfit. Only to have that stripped away. Without them, who am I? I could not hate it here more, but I obliged. Minutes passed and my surgeon came in. He signed my stomach, which confused me. It made me feel like an object or a piece of work, so far from human it was unsettling. But I guess him signing my stomach meant that I was ready. So, I blinked those feelings away as the IV was hooked up at this point and the nurse switched the drip from saline to anesthesia.

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That was a nice nap. The best sleep I have had in a while, even though I never wake up rested. Sleep has been a struggle lately, so it was nice that for a moment, I felt good. Groggy, but good. And then I moved. I was abundantly aware of the incisions now present on my abdomen. I told myself that I knew this pain was coming, and that I could handle it. My vision slowly cleared up, and I could see my parents on the right side of my bed. They were always there, for all of us kids, and I liked that. I often take that for granted. This part of my life gave me the opportunity to hold onto the consistency of love from my family.

Argh. I moved again and the pain shot through me. I open my eyes and try to access the situation on my abdomen. I cannot bend that way right now. I asked the nurse to take a picture. I want to see what I am in for. How difficult is this recovery going to be? The nurse handed my phone back and I studied the picture she took.

Figure 4- LT Post Surgery

Zoomed in and out. Noticed the incisions. Noticed the initials on my abdomen. Noticed the glue holding me together. Glue was the only thing between my insides and the real world. I hope it is stronger than Elmer's glue.

I find it almost funny that everything was resolved so quickly with the last doctor I saw. It kind of makes the five years of pain fade away in a sense. It almost makes me wonder why this problem could not have been resolved sooner. I mean, it took, from the moment I met the doctor to the moment I was out of surgery, about two months. That is a fraction of the time I spent trapped in the revolving door that is the health care system. That baffles me. The issues with my intestines were fixable, and they could be fixed quickly, I just was not given the time of day. That hurts me when I let it. This work of writing is me trying to not let it hurt me. I want to use these frustrations to fuel my research to hopefully prevent this for others in the future. We should all be treated well in the health care system. We should all be met with doctors that care and want us to feel better. So, my problems were addressed quickly and efficiently when I was met with a doctor that cared. I am still grappling with frustrations lingering from the previous doctors, but I am hopeful that change can be achieved in the system and patients can be met with better care.

CHAPTER 7: HEALING

In the weeks following surgery, I was back on campus and my family was far away. As my incisions healed, the glue keeping them closed began to fade. In my mind, the incisions were creeping towards busting right open. I called home, late at night when my parents should have been asleep. They answered and the tears came instantly for me. My parents thought I was in pain, they were panicking. The first words I got out were “my guts are going to fall out.” My dad started to laugh, he quickly replied, jokingly, saying “Bun Bun, that is crazy.” I explained to them that the glue was dissolving. They explained that was meant to happen. But how was I supposed to know that? It turns out that the doctors droned the details of what I should expect post-surgery while I regained consciousness from the anesthesia induced sleep state. How was it ok for them to do that? I am struggling to see doctors as the “good guys” still. They helped me, yes, but they failed to guide me and support me during my healing.

Time is confusing. We know that. It ebbs and flows. It speeds up and slows down. Especially in our memory. Looking back, I feel pretty numb to all of these struggles that I faced. Like they were so difficult and troubling that my brain won’t let me time travel back to that time. Like it is in a back room, boarded up and locked off. I think it is likely guarded by security as well. My brain will not let me access the deep struggles I faced. I keep getting my thoughts muddled when I consider what I went through. It is not an easy task, letting someone read your story. Opening up your mind and heart is scary. But I am trying. In my attempts, I have let a handful of people read drafts of my work. When they give me feedback, they instantly address my health issues by stating “your eating disorder” this, “your eating disorder” that. I am having a hard time grappling with these comments. It helps that I am numb a little bit. But it confuses me. Why are people diagnosing me? Why are they clinging to their assumptions? I think I could not get people to understand what I was feeling and what was going on, because I did not understand. I was not given enough time to share what happened effectively and that left room for the readers' minds to wander and assume. They were looking at what could have been versus what the reality of the situation was.

I feel the need to explicitly state I *did not* have an eating disorder. Why is everyone telling me that is what was going on? Like they know me? Like they know what was going on? The doctors don’t even know. How would random people know? I might have had disordered eating habits. I might have had difficulties accepting and choosing food. But that is not by choice. That is where things vary. The truth is I don’t know what was happening with my body. I know I could not keep food down for years. But that was not without attempts and a deep love for food. I know I threw up most of my food. But that was uncontrollable. My body refused to digest food, so throwing up was the only option. I know that I had to get surgery to be able to keep food down. I know I had a skewed relationship with food after this surgery. But is that not ok or acceptable? I want you to try to imagine struggling to eat food that you love for years and all of a sudden you can devour any food in sight. I needed to rewire my brain to feel ok with this new reality. Sometimes I touched the wrong wires together. The weight gain was seemingly instant. But it was bound to happen. My body was no longer restricted.

The dinner time with my family was significant because it kept me grounded. My relationship with food was misconstrued and tainted. They were the reason I held onto taking care of myself in some capacity. Family dinners in my house were set up to be intentional time, which encouraged me to love food. My dad would cook, while we would all hang out in the kitchen and set the table. Then, we would sit down together and share a meal. For an hour or so, we would bounce around ideas, share about our days, and enjoy delicious food.

And then came my weight gain. Following surgery, I gained 20 pounds. Of healthy weight? Yes. But that is hard to acknowledge when people make comments about your new appearance calling out that I looked bigger, or rounder in the face, or needed to work out. That was humiliating and led to a downward spiral. How could it not? I was finally able to fuel my body and gain the nutrients I needed, yet I was shamed for it. However, the time that I got to spend with my family around the table helped me remain grounded. While other people follow different paths to getting better, I know my family was a crucial part of my recovery.

The healing came in waves. The weeks after surgery were chaotic, to put it simply. My family, seemingly abruptly, moved across the country. My dad's work moved us around a lot. But this one was different. I was an adult, at school, on my own. So, they moved, and I stayed. That would be hard enough as is, but I was still healing in the midst of the move. Mere days apart, I learned of my pending surgery and the pending move. Mere days apart I got surgery, my family moved, and I was back at college. The whiplash still has me reeling. But in some ways, the chaos kept my thoughts preoccupied.

A few weeks after that, my family reunited for a weekend trip to Florida. Disneyworld, to be specific. I always loved it there. I still had the remnants of glue over my incisions. I was hyperfixated on that as we waited in line for my favorite ride, The Tower of Terror. This drop ride normally gave me such a rush. The slow and steady anticipation paired with the thrill of the floor feeling like it gives out beneath you left me on a temporary high. Today felt different. As I waited in line, the panic set in. One tear became two, became a hundred. At 19, I wept like a child. I looked to my family and said, "my guts are going to fall out." This was a reoccurring fear for me during this time in my life. I think I am facing this fear through my writing as I "spill my guts" and let this story live outside of my thoughts, I find that ironic. At the time, I did not know any better and this fear consumed me. My doctor did not tell me what to expect. The tears turned to laughter. I became aware of the children around me, who were actually scared of this ride. I was getting unwanted attention. My parents calmed me down, they told me it was weeks past my surgery, and I would be ok. I trusted them and endured the ride. My guts stayed on the inside of my body, and I left The Tower of Terror with the rush I always do. I loved that ride. My stomach was fine. I was fine.

This level of panic would hit me from time to time. When I least expected it to. When I found myself creeping close to panic, I found music to be the answer. Taylor Swift's music. Her lyrics spoke to me and continue to do so:

"Only rumors 'bout my hips and thighs" -- *Is It Over Now?* (Swift)

Commentary: Looking back, I felt like the people around me hyperfixated on the areas of my body that, as a woman, are supposed to look a certain way.

"Starved my body" --*You're On Your Own Kid* (Swift)

Commentary: My initial thought is to say, "self-explanatory." But if I were to expand on that, I would say that this highlights the habits I struggled with. My body went from restricting food to opening the flood gates. I had to learn how to eat again. In doing that, there were days where I would forget and feel like I was starving.

"The bottom's gonna drop out from under our feet, I'll catch you, I'll catch you" --*Jump Then Fall* (Swift)

Commentary: My family comes to mind with this lyric. Everything was crumbling, I was falling apart during this time, but there they were. Ready to catch me.

“You have knocked me off my feet again, got me feeling like a nothing” --*Mean* (Swift)

Commentary: The words of others put down my self-esteem and left me feeling empty.

“We learn to live with the pain, mosaic broken hearts” --*State of Grace* (Swift)

Commentary: The pain was always there during these years of my life. I was living through it.

"The water filled my lungs, I screamed so loud but no one heard a thing” --*Clean* (Swift)

Commentary: I felt so isolated, so alone. I wanted people to see that I needed help, but no one outside of my family saw it. That hurt.

“I hate my reflection, for years and years” --*Archer* (Swift)

Commentary: This song came out following my health struggles, but it encapsulates how it felt to look in the mirror during that time.

“Hey, it’s all me, in my head, I’m the one who burned us down” --*Afterglow* (Swift)

Commentary: This song, looking back, highlights me gaslighting myself during that time. I was convinced I was making it up because doctors couldn’t help me.

“What should be over burrowed under my skin in heart-stopping waves of hurt” --*The Lakes* (Swift)

Commentary: This song came out following my experiences, but I feel like it highlights the fact that the feelings still live within me. I can’t fully rid myself of them.

“You held my lifeless frame” --*All Too Well (10 Minute Version) (Taylor’s Version)* (Swift)

Commentary: I felt sick and weak, I felt like I was not even living.

Some of those lyrics came out after I experienced my health struggles. There is a method behind the madness. Healing is not linear, it takes time. I think I am mostly healed but I still have bad days like any other human being. Her lyrics somehow still are able to pull me out of my negative thoughts. Even if they are lingering thoughts from the past. Her music calms me down. Most music calms me down, excluding rap and hip hop and loud stuff like that. Research shows that music has the ability to "lower our heart rate and cortisol levels, release endorphins and improve our sense of well-being, distract us, reducing physical and emotional stress levels, reduce stress-related symptoms, whether used in a clinical environment or in daily life" (Collins). Maybe that is why I feel drawn to music, without knowing it is having these healing effects on my mind and body. Healing takes time, we know this, so I continue to turn to music.

I find the concept of healing to be so intriguing. It is defined as, "the process of making or becoming sound or healthy again" (Oxford Dictionary). But what does that even mean? How do we define healthy? I think I am healthy, but if I have a random stomachache, or a random headache, does that mean I am no longer healthy and need to resume the process of healing? Or are we in a constant state of healing? I struggle to understand if any of us are really healthy. People on heavily regimented diets and workout routines—is that good for you? People that eat junk food—we know that's not good for you, but what about on occasion, I love dessert, and treats. *Does that mean I am unhealthy? I think I am healthy. I hope I am healthy*.

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I threw up in the Costco bathroom at 21 years old. Two years had passed since the last surgery. But throwing up was apparently still a trigger. I need to shake that. I feel this sort of numbness around all of it. I was walking through the store, and I felt so nauseous. I must have eaten something bad or smelled something bad. It could have been the drive there, maybe car sickness. But it was not a relapse of my stomach issues; the doctors told me that could not even happen. But this would not be the first time they lied to me. *Do I believe them? I think I should, I think I am ok. Just some nausea, that is normal, I am fine.*

Looking at food was not helping in the slightest, it escalated the situation at a rapid rate. I rushed to the bathroom and made myself get sick. I know the signs before I am going to throw up. I started to get warm and sweaty. Saliva starts filling my mouth and I swallow it quickly to try to push off the inevitable. But after all the years of throwing up, I have grown tired of waiting for my body to throw up. The nauseous feeling lasts for so long and makes it even worse. So, in the Costco bathroom, I take matters into my own hands and speed things up. It is times like this when I realize how my story got blurred in the minds of others. I did not eat much, I threw up a lot, I sometimes made myself throw up. I know how that looks: signs of an eating disorder, when the context is lacking. I did not eat much because my body could not digest it properly. I threw up a lot because the food would sit in my stomach and my body would attack it with acid to try and help the food move from my stomach to my intestines. All of its attempts were unsuccessful because of the narrowing in my intestines. And I made myself throw up because I knew what was coming, I saw no point in waiting. *I never claimed to be a patient person.*

CHAPTER 8: APPLICATIONS

The story I've told thus far has been a recounting of my difficult experiences and struggles over the course of five years. While I see the value of sharing my reality, I have also undertaken this project for the sake of community. My hope is that sharing my story, and examining it in connection with established facts about our healthcare system, will highlight where the healthcare system falls short and where society places people into boxes. How difficult my life was for five years. How many surgeries I had. How I struggled mentally. How people's comments hindered my healing. How the health care system screwed with me. How all of this combined and separated and wove together to alter this chapter of my life. My case does not stand alone. The health care system tends to rush patients in and out of doctor's offices and hospitals. People we encounter within society tend to comment on physical appearance. And wrapped up in both of these issues is the idea of gender. My desires and hopes for this work of writing are rooted in a need to improve the field of my future career in Health Care Administration. The hope is that this work can kickstart my fight for change throughout my career.

I also share my story in the hope of creating a better society. Society is overflowing with pressure. Pressure to be a certain way, act a certain way, fall into certain norms. Men are expected to be strong, emotionless, and the provider. Women are expected to be thin, beautiful, patient, kind, quiet, passive, unopinionated and the caregiver. While both genders face societal pressure and expectations, women's struggles are much more apparent and historically overlooked. They spread across disciplines and areas of life. They worm their way into home life, school life, work life and health care.

I felt these expectations and pressures make me crumble. The Pew Research Center considers what is expected of women when it states, "the top qualities for women are physical attractiveness and being nurturing and empathetic" (Parker et al., 2017). Of the U.S. citizens surveyed, 35% of them said physical attractiveness is what they expect from women, which was the highest scoring quality (Parker et al., 2017). That is so vague and subjective. What does it mean to be physically attractive in the United States?

The beauty stereotype includes, but is not limited to "long hair, skinny and thin, makeup, plastic surgery, dyed hair" (Jain).

I matched these stereotypes, mostly, when I was sick. I had achieved the model look, and those around me were quite vocal about that. The appearance I had achieved through years of illness was praiseworthy. And for a while I was ok with that. I did not know any better. I was not even aware that I was sick or that something was wrong for years. So, the comments were nice. Girls are trained to enjoy being called pretty or beautiful. It gives us a rush. Arguably more so than comments about how smart we are, how kind we are, how thoughtful we are, how funny we are. We are trained to seek comments on our physical appearance. And my sick body was rewarded with those comments.

Those comments were the complete opposite of what I was subjected to during or after I was healed. I was no longer meeting society's nearly unattainable standards. They were only met when I was deeply ill. And now that I was deemed healthy by the medical system, I was shamed and disrespected by those who had seemingly seconds ago told me I was pretty. Now I was fat in their eyes. Without a doubt, the shift in language surrounding my body hindered my healing process. How could it not? I am not alone in this, women as a whole, are expected to be a certain way and look a certain way. This deeply rooted flaw in society impacts the mental and physical health of women. I urge the reader to consider the way they talk about their body and the bodies of others. Consider why. Consider unlearning that bad habit. Consider choosing kindness towards oneself and towards others. Consider leaving comments about the human body out of conversations. After all, many people suffer from body image issues and this kind of public discourse significantly contributes to the number of people struggling with this health issue.

Let's push past this frustration and consider the time patients have to wait for an appointment. Sit back and consider when you have been ill before. So sick that you must see a doctor, but not emergency room level. You want to get in and see your doctor and are stopped in your tracks when you call to make an appointment. You are now informed that, "average wait to see a new doctor is 26 days and getting longer" (Time Magazine). The waiting continues, the pain ensues. Time pressures are a direct result of the extensive number of patients seen daily. It is overworking providers.

When we enter a health care system, we seek guidance and understanding in regards to our body. We trust that our health care providers, having studied for years, can provide us with that. We trust that they will give us an adequate amount of time to address our health concerns. We do not anticipate that we will be granted, on average, "17.4 minutes. The median length of visits was 15.7 minutes. The median talk time by patient was 5.3 minutes, and physician, 5.2 minutes. The median time during which neither part spoke was 55 seconds" (National Institute of Health). I wonder if this is relatively common knowledge, or if we all possess some level of awareness of the scarcity of time we possess with our providers, how we tolerate it.

Furthering this thought, you discover how many patients the doctors are expected to see in one day, "A 2018 survey found that most physicians saw between 11 and 20 patients per day. A small percentage, 1.3%, saw between 51 and 60 patients each day" (Elation Health). This survey highlights how filled up doctors' days are. This does not include meetings or lunch breaks. They have so much to do during the day. So, with minimal time, energy, and the constant awareness of burnout, how can we expect our doctors to provide for us? I grapple with this question a lot. My health journey is rooted in my frustrations towards health care providers. But I feel as though I have faulted the wrong party. Doctors are expected to meet with so many patients a day and help them feel better. They must be quick on their feet and up to date in their health care knowledge to see a patient and know what is wrong with them in 15 minutes or less. The structure of doctors' offices and hospitals is impacting their ability to effectively do their job. They are restricted by time and can only help so much in that amount of time. They are also expected to switch gears and help their next patient shortly after their last. This is not setting doctors up for success.

I wonder if my lack of diagnosis was a result of the minimal face to face time I was granted or a result of my potentially ineffective communication skills and my limited vocabulary hindering my ability to articulate the complexity of my condition. This could be true, but is it my responsibility, as the patient, to be able to effectively voice what is going on? Or is that the fault of the provider for not asking the right kinds of questions to ensure they are getting the important information? I find it to be unfair and unrealistic for providers to place the communication responsibility on a non-doctor when it comes to communicating medical concerns and information.

The communication barrier spreads even deeper for patients who do not speak English or are too young to understand the pain or discomfort in their body. The unfair expectations of the health care system are rooted so deeply in time barriers. The system fails the providers, the providers fail the patients, the patients stay sick, the cycle continues.

There is no clear answer to the question of "why did my health condition impact my life for so many years?" and gosh, do I wish there was. I wish I could understand why time was controlling me for so long. Yes, my health issue was a problem. But arguably the length of time it impacted me was a larger problem. What I do know for certain is that the health care system is truly and deeply flawed. There are barriers to health, no matter your income, insurance or location. The Center for Disease Control states, "Socioeconomic factors affect one's ability to engage in health activities, afford medical care and housing, and manage stress" (CDC). Imagine if my parents did not have good insurance, how much farther back would I have been set? Everyone faces some level of barriers to health. This is an intrinsic flaw to the system, that unfortunately cannot be solved overnight.

Socioeconomic factors do play a significant role in personal health and access to health care. Research shows that "Access to, use of, and quality of health care vary by socioeconomic status. Among adults, 40 percent of those who have not graduated from high school are uninsured, compared with only 10 percent of college graduates; more than 60 percent of the uninsured are in low-income families" (Health Affairs). Health care insurance is a huge topic of discussion. The issue becomes affordability and quality of coverage. Coverage is so variable and out of pocket costs can be steep for those that do not have good insurance. Insurance, in itself, is expensive and does not include out of pocket costs. Sources show that, "The average monthly premium for a bronze ACA health insurance plan is $420 for a 40-year-old. The average monthly cost for that same person increases to $549 for a silver plan and $713 for a gold plan" (Forbes). Now, it is one thing to acknowledge that there is an issue, and another to understand why. Further research uncovers that "Health inequities stem from structural inequities, the systemic disadvantage of one social group compared to other groups. Structural inequities are deeply embedded in the fabric of society, encompassing policy, law, governance, and culture" (National Academy of Medicine). The problems with health care are not contained to the health care system. They are the result of politics, societal norms, historical events, finances, etc. That is why so many people say that health care is a mess or the health care system is bad, but fail to make signficant change. It requires commitment to advocating and fighting for change inside and outside of the health care settings.

If you asked me prior to my health experience, what I wanted to pursue as a career, I would have told you an artist or a teacher. Easy. That was my answer. But it never felt fulfilling. And then, in the blink of an eye, my life was swept up in this whirlwind of health struggles. I felt called to do something about it. No one should feel how I felt, yet my story is not the only one like it.

Research shows that "In the United States, 12 million people are affected by medical diagnostic errors each year. An estimated 40,000 to 80,000 people die annually from complications from these misdiagnoses. Women and minorities are 20 to 30 percent more likely to be misdiagnosed" (Healthline). These statistics are aggravating, annoying, and upsetting. How is this not talked about more? How are we not doing anything about it? I hesitate to wonder what would have happened to me had it not been for that doctor that took the time to understand what was happening and get me the life-changing surgery I needed. That is a scary thought for me, but a reality for others. The added information of women and minorities having a higher likelihood of misdiagnosis is annoying but not shocking. These populations are already vulnerable in our wider society, and this shows that they are also vulnerable in the context of health care. The National Academy of Medicine "found that "racial and ethnic minorities receive lower-quality health care than white people—even when insurance status, income, age, and severity of conditions are comparable." (ABA). I wonder if this played a role in my misdiagnosis and lack of diagnosis. It has been stated that, "More than half of women believe their health issues have been misdiagnosed. As if women don't have enough to worry about, new research has revealed the extent of medical bias, with as many as 57% of women reporting being wrongly diagnosed by doctors" (*Cosmopolitan*). The never-ending list of areas when women are disrespected and mistreated continues to grow and plagues our health care system.

Growing up, I had heard that the health care system was a mess, or it sucked, or whatever other variation of these messages you can imagine. But that's all that happened, I heard it. Then I was 16 and confined to four walls of a hospital room. Then I was 17 and 18 entering and exiting doctor's offices in the same second. Then I was 19 getting a surgery to fix everything. Then I was 21, finally having gained courage, sharing the story. Then 22, on the brink of entering a career in Health Care Administration. It is hard to see or understand the structural flaws in healthcare until you experience them firsthand.

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I found myself in a hospital waiting room during my writing process, not for a friend, not for a family member, not for myself; I guess let's call it field research. I realized I have never been in the post-op waiting room. Waiting for results, waiting to hear how surgery went, waiting for updates. I was always the one in surgery.

I found a quiet corner, but not too far away from patient family members and pulled out the book I have been reading, one of my typical romance books. And while it looked like I was reading, I was watching and listening those around me. I overheard conversations updating other family members, I watched people pace, I watched people go through too many coffees. But one conversation struck me. The family had been waiting in the same chairs for three hours, they had voiced their frustrations about the duration aloud. They had been kept in the dark about the state of their loved one in surgery. After the long wait, they found out the nurses and doctors had relocated the patient to a new room a while ago, and she was recovering but in pain. They shuffled together their belongings, clearly wanting to rush to that room. On their way out, I overheard one of them say, "You know, the care here has been amazing, but the communication, ehhhh, it is what it is." No one deserves to face these communication issues, and clearly it stems deeper into the health care system than most think. It impacts patients, but also their families.

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"Dear Reader,

Burn all the files, desert all your past lives
And if you don't recognize yourself
That means you did it right" (Swift).

What do we do when we are left with only broken pieces of our past selves? Search for who we were? Strive for who want to be? I choose the latter. I firmly believe that everything happens for a reason, it is our job to learn how to cope with suffering and learn from it. Taylor Swift mentions, in her song *Dear Reader*, that once we reach that point that we do not recognize ourselves that we have met our goal. I am not who I was, I am not who I am going to be, I am still learning who I want to be and where I want to go.

I am in this pivotal moment where I can sense change brewing and see hope for the future. I am left pondering questions that used to strike me hard:

> How often do you judge and loathe yourself when something goes wrong?, How often do you crumble to unworthiness when someone you love does something that hurts you?, and How often do you experience anger and envy toward others, when you actually want to feel happy for them? (Itani, 2021).

I felt like these questions resonated with me and how I was feeling at that difficult time in my life. I was crippled by my feelings, by my doubts, by my negativity and by the health care system. That is a paralyzing feeling. Life slows, colors fade, feelings drift, and loneliness stays. Loneliness is a residual feeling that looms and lingers in the air. We breathe it in and some of us are lucky enough to breathe it out. For others, it gets stuck within us, and it is hard to shake.

This work of writing is an attempt for me to expel the loneliness that is lingering around me and within me. Loneliness through my struggles, loneliness in my feelings, loneliness in my experiences. With that in mind, I present this quote:

> Narratives are especially important in the transpersonal paradigm because they form the core of ‘‘nuances of our personal identities’’ (Braud & Anderson, 1998, p. 23). In the act of sharing these nuances, a story is told, a past is remembered, and insights are formed as a way to cast a light on a lived experience. By sharing narratives the participants became more aware of their pivotal or transcendent experience. Thus, as Braud & Anderson stated, “a more fully enriched spiritual awareness seems not only possible but more probable” (p. 24) (Raab, 2014).

I am remembering and moving through my experiences, and I am attempting to forget, I think. the beginning of Taylor Swift's *All Too Well* short film quotes Pablo Neruda: "love is so short, forgetting is so long." I am trying to push back on this thought, to push past the forgetting and make space for myself and others, and to thrive in the happy parts of life like love. With every word I write, I am marching closer to my goal. I want to do this right, do this well, and end up feeling recovered and healed. Do I want to fully forget? I am not sure, but I don't think so. That would be ignoring a pivotal part of my life that led me to the point I am today. The good things in life would be seemingly insignificant without the black and white contrast of the bad. The health struggles I faced allow me to be joyful in the present: to be grateful for the life I have, the family I have, and the body I have.

So what, who cares? I do, the people around me do, and that will, hopefully, cause a chain reaction to lead to others caring about this project and seeing the potential for the good it can bring about. Whether that is helping one person or many, the goal will remain: to help others. I want to attempt to mitigate the levels of loneliness I felt, in the lives of others. I want to push back on the deeply rooted issues in health care that are leading to things like misdiagnosis. My hope is that this writing may be my first step. And my career in health care administration will be the marathon I run to achieve this goal.

CHAPTER 9: CONCLUSION

Memoirs are an opportunity for processing and sharing for the writers, and for encouragement, education, and inspiration for the readers. Change does not happen overnight, and that is not what I expect to come out of this work of writing. I know that the impact it will have could be very minimal. No one might read it outside of my family, Regis students and faculty, i.e., those who are somewhat obligated to read it. But that glimmer of hope and possibility for someone to read it who is going through something similar with medical misdiagnosis or knows someone who is having similar lived experiences is why I feel called to write this. Hearing someone really dive into what they went through would have eased my mind and made me feel less alone. It would have given me a sense of community in a time that I felt so lost and afraid. A time when the health care system failed to care for me. A time when I felt like I was the only one who has experienced this. But I know now I was not alone, I was one of millions. Having a sense of community would have taken away some of my stress and confusion. It would have confirmed that my feelings are real and valid.

For those who are reading to understand the effects of the flawed health care system, or those in the thick of their health care struggles, I encourage you to advocate for yourself and those around you. Before your doctor appointment, or on the way to the hospital if it is urgent, formulate your thoughts in a notebook or in the notes app on your phone. Take note of what you are feeling, any health concerns you have, and any questions you have for your doctor. This will help you maximize the face-to-face time you are granted with a provider. I have found when I go into appointments unprepared, I get rushed and forget about the questions I wanted to ask. Being prepared allows me to ask all the questions and get all the information I need. I encourage you to help family members and friends do this as well. It is a small change but it can help utilize the short appointment time effectively. I also encourage you to look into your insurance coverage. Seek to understand what other providers your plan covers so you can get multiple opinions on your health. This will ensure you get answers, I truly believe this is how I got better. Health care is frustrating; this is not news to many of us. But it is not flawed beyond repair. When I gain a leadership role in a health care setting, I hope to chip away at these flaws and lay the foundation for those who will come after me. I am hopeful because I have chosen a career that will give me the space to do something about the issues in health care related to quality, cost, and access.

My family is one of the reasons I am healthy today. Not everyone gets that opportunity to have a supportive family unit to lean on every day, even when they are not fully aware of what is going on behind the scenes. I can remember calling my older brother while we were both away at school and not telling him anything that I was struggling with in terms of my body and relearning how to love food. But hearing him tell me about his day and week calmed me and reassured me that no matter what, I had him. This remains the same to this day. Feelings of loneliness only go as far as we allow them to. My family would not allow those thoughts to get really far for me. So, while I struggled, I cried, and parts of me died, other parts of me grew, changed, and were reborn.

If the reader forgets the thousands of other words that mark up these pages, I want them to remember this: health care is complicated, it extends beyond the hospital walls and even when you are physically healed, it may take your mind some time to catch up. While I consider myself to be healed, I still have days where the doubts creep in, which is normal. Healing is not linear. I remind myself that I need to remember to appreciate the good times while I am in them.

Everyone faces challenges in their lives, but that is how we grow and learn as human beings. Lived experiences are the best way to learn about ourselves and others. That is the way I look back on this time of my life. I look back and think about how difficult it was, how much self-hatred I felt in my heart, and how much I struggled to maintain a healthy lifestyle. I also look back and think oh my god, I would not be the person I am today without that experience. I am the healthiest I have ever been, but I do not take that for granted, I celebrate my body, I give myself grace, and I hope I can encourage people to do the same. All of this comes with time. And with healing.

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