

A Poetry Collection

Poems on Family Caregiving

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Abstract

The eldest sibling in a family usually bears more responsibilities compared to their younger counterparts, a difference widely discussed across the media; however, there is another interesting sibling dynamic that goes significantly unnoticed. Within families that have members who experience disability, the able-bodied sibling gains the obligations often cast onto the eldest child. In contrast to the older sibling phenomenon, the able-bodied sibling receives greater responsibility regardless of their place in the birth order. *Not Simply* is a collection of poems that describes my experiences as an eldest daughter and the able-bodied sibling in my family, expressing the journey of learning who I was in the midst of strong family bonds, a conflicting relationship with caregiving, and being split between the two worlds of ability and disability. These poems shed an important light on how the line between ability and disability is blurred within these families, further blurring the line between what is defined as *normal* and what is defined as *different*. On this blurred line, I come closer to finding the clearest image of myself as I explore the powerful influence it had on me as an individual.

Stairs to Steps to Poetry

The idea proposed for my thesis project did not come to me in the early stages of my brainstorming process; but rather, was born out of a desire, kept hidden and almost forgotten, stirring in the back of my mind ever since my parents made their one and only Youtube video when I was six years old. The video was titled, “Stairs to Steps.” It was a hopeful, albeit tad melancholic, montage of my siblings and I going about our day.

We were filmed playing in the living room, entering and exiting our house, and completing our daily routines. At the time, we were living in a two level house with a sunken living room. Three different sets of staircases in the hilly terrain of Salem, Oregon was not the ideal situation for children with physical disabilities. This prompted my parents to begin sharing their story, along with their family’s needs, in the hopes of gaining enough financial support to purchase a one-level house or property to build on.

In making the video, my parents heard from other families and found a loving community which endured even after my parents’ original goal had changed. I watched that Youtube video over and over again as if it was my secret obsession. I was enamored by the prospect of putting something out into the world that had a meaningful impact. And so began my longing to create an extension of myself that connected and resonated with others in the hopes of us all feeling a little less alone.

When my fifth grade teacher assigned me the novel, *Wonder*, by R.J. Palacio, I was once again transfixed. Not only was this the first book I had read that featured a main character who experienced disability, but it also was the first book I had read that included the perspective of the protagonist's older sister. Almost everything the sister character expressed and experienced was similar to what I felt or went through. As I read this novel, I was *seen* by literature, relying on the sense of safety that understanding brought me for years to come.

It was not long after traversing Palacio's written world that I read, *Out of My Mind*, by Sharon M. Draper. This novel allowed me to enter the mind of a character who had the same diagnosis as my siblings: Cerebral Palsy. The level of intimacy between the reader and character was one I had always wanted with my siblings. I desperately wanted to understand who they were past their exteriors. When I was younger, I often asked myself: *What is he/she feeling right now? Am I doing enough? Is this enough?* This novel gave me greater insight into the possible thoughts of my own siblings who cannot always verbalize their feelings. These two novels, *Wonder* and *Out of My Mind*, affected me deeply, both reminding me of that longing I felt earlier in childhood and sparking a new question: *Would my own experience be worth sharing?*

If someone had asked me two years ago what form I would choose to share parts of my life in, my answer would have only involved writing a novel. I had always imagined that some day, I would sit down at a desk with a romanticized perception of me click-clacking away on a typewriter to complete my novel. I was

so confident that this would be my eventual path in literature, an idealized hobby in the future at the very most. Then, I took a literature course at Western Oregon University that required I read Natalie Diaz's collection of poetry called, *Postcolonial Love Poem*. Suddenly, my path re-shaped itself into something new.

Postcolonial Love Poem was one of the most beautiful and fluid texts I had ever read. Diaz's work exposed me to the richness and complexity of poetry in experimental forms. I was enamored by her style and voice, blasting through the boundaries that I thought constrained poetry. She had a much more limited time to strike me as a reader – use every word and its positioning to impact me with intention. But Diaz did it in a way that was just as impactful as it was digestible. Hers' and my life were entirely different from one another, and yet, I felt connected to her in a way I had not experienced through writing before because it was as if she gave me permission to tap straight into her stream of consciousness. And at the end of the day, that's exactly what I think poetry is. After placing her collection back on my bookshelf, her words and rhythm played in my head over and over, shaking a memory loose I had completely forgotten about.

I once read that writers often produce the mediums they gravitate towards the most in their lives. For me, I had always thought that was the novel. But when Natalie Diaz spoke to me through her poetry, something about it was familiar. The words were different, however, the language of its form was recognizable when I had thought this was my first time interacting with free verse in a longer narrative. Finally, I remembered that as a child, I went through a phase of reading free verse

books. My favorite book in the third grade was, *Inside Out and Back Again*, by Thanhha Lai. Today, this book sits on most teachers' bookshelves and can be found in every library.

When it was freshly awarded the National Book Award, I had tripped right into it – literally and figuratively – as a reader when it first hit the shelves of my school library and was the new up and coming children's book in verse. Again, there was something about this book that made sense to my brain but was soon covered by a plethora of chapter books as the more popular choice of those around me. Nonetheless, I rediscovered my love for this genre when I read the pages of *Postcolonial Love Poem*. In doing so, I realized that this writing form felt *right*, like returning home from a long journey. Even though I had little experience working with this craft, I knew I had to try and this thesis project gave me the perfect opportunity to do just that.

Literature Review

In recent years, poetry has gained a dramatic increase in popularity within mainstream media as more people of the younger generation choose this medium of expression. According to a study conducted by the National Endowment for the Arts in 2017, “the share of 18-24 year-olds who read poetry more than doubled, placing this age group above all others when it comes to poetry-reading rates” (Hooper). Poetry allows the writer to express a spectrum of emotions and experiences through shorter amounts of text, “capturing the essence of moments or the depth of feelings with precision and brevity” (Peiris). With the advancement of technology, people have become accustomed to fast-paced absorptions of information and entertainment; thus, people are more inclined to create and read works of poetry for their personal enjoyment and virtual audiences. Contemporary, or modern poets are utilizing this rise in readership to transform their writing into works of advocacy, experimentation, and tools for justice. Not only do today’s poets accomplish these aspirations, but they also strive to relate to readers as they are exploring complex emotions influenced by the everyday as well as national events.

Poetry has become one of the most accessible and inclusive art forms through “its dedication to diversity and inclusion. Today’s poets hail from a broad spectrum of backgrounds, each contributing their distinct narratives and viewpoints” (Peiris). Poetry, in its most basic form, is founded on its poet’s description of experience, whether that be a physical or emotional one. As time

progresses, and people change how they think or behave in certain situations whilst those very situations are also subject to change, what is known as the human experience and the human condition alters; therefore, the dramatic changes that have occurred in quick succession of each other over the past decade has elicited a transformation in how people perceive society, others, and themselves, causing them to explore different modes of expression. One of the most effective forms of expression is the written word, and in particular, poetry.

Poets who have received high praise on social media platforms and are critically acclaimed for their poetry, share thematic and stylistic characteristics even as they navigate individual hardships, journeys of self-healing, and address separate issues within greater society. Rupi Kaur and Rudy Francisco have gained immense popularity for their poetry over the past couple of years due to becoming “trendy” on social media. Rupi Kaur, specifically, rose to poetry fame on her Instagram account. These poets were well into their craft by the time they became internet famous, however, their popularity allowed the poetic form to quickly gain attention. Rupi Kaur and Rudy Francisco both write predominantly in free verse, shifting between different line lengths, poem lengths, and visual style. Kaur’s poetic style is more artfully simplistic than Francisco’s as he tends to write mostly in prose. However, each of them explore their own experiences with loss, love, and cultural and emotional healing.

Kaur’s breakout poetry collection, *Milk and Honey*, is organized by its overarching themes: *hurt*, *love*, *heartbreak*, and *healing*. She addresses each of

these distinct themes with poems that range from two lines of free verse to three whole pages of prose, extracting quick spurts of emotion to draw out expressions of anger. Many readers appreciate Kuar's honesty about her experiences with sexual violence and her compassion for her readers as she directly talks to them through advice poems, which are sprinkled throughout her collections. Rudy Francisco is well known for his spoken word poetry, but quickly gained further prevalence for his poetry collections. In *Excuse Me As I Kiss The Sky*, his most recent collection, Francisco utilizes four different poetic forms to connect his experiences with the everyday mundane to powerful emotional responses and cultural events. These forms include the golden shovel, contrapuntal, ode, and the obit. Francisco chooses each word carefully and blends them together within these different structures while inspiring his readers to do the same. Both of these contemporary poets are leaders in this modern poetry movement that wastes no time with getting to the nuanced elements of the human experience with precise imagery and powerful language.

The experience of disability is a largely discussed topic within literature, from first person perspective narratives to works that promote anti-ableism. In 2013, the Schneider Family Book Award was founded, providing national recognition for children's and young adult literature that highlighted the stories of people who experience disability. The most popular works that have won this award "simplify neither daily frustrations nor larger, systemic difficulties faced by disabled characters, and they refuse to overly complicate, to place a beyond

understanding, disabled lives” (Meyer Ch.1). Although the disability community’s literary presence, including its literary acknowledgement, has increased over recent decades, works involving the perspective of an able writer or character whose story is significantly affected by their siblings’ own unique experiences with disability are still greatly underrepresented within this literature.

One of the most well known works within this literary space is titled, *Being the Other One: Growing Up with a Brother or Sister Who Has Special Needs*. The author, Kate Strohm, describes her own experiences growing up with an older sister who was diagnosed with cerebral palsy. In her novel, she identifies, “although I had a true sense of belonging as a child, with deep connections to a loving family, I also felt alone and afraid” (xi). Strohm shares how she struggled with being the able child in her family, unable to find help until later in her adulthood as her therapists and psychologists were unfamiliar with the potential negative effects on the “other sibling.” She explains how connecting with other siblings from similar experiences allowed her to recognize the significant gap in the literature that explore these stories.

Even though Strohm acknowledges the existence of other literary works that do provide perspectives similar to her own, she emphasizes how, “Until now most of the stories we have heard from siblings reflect a positive experience, because those are the easy stories to tell. It seems they are the only stories that society wants to hear” (xiii). Therefore, there is a considerable lack of honest, unbiased representation of disability and its effects on interpersonal relationships

explored through literature. More recently, there has been increased research on the socio-psychological impacts of sibling order, specifically the phenomenon known as the Eldest Daughter Syndrome. Although this does not directly relate to the literature discussed by Katie Strohm, it does significantly correlate with many of the first person accounts she documents in her book. Most of the individuals she interviewed were either mothers of an individual who experienced disability, or the eldest sister of a sibling with intellectual or physical disabilities.

As the literature has grown in relation to the responsibilities of eldest daughters, there has been much correlation observed between these responsibilities, with their socio-psychological effects, and the responsibilities of the able sibling in a family. For instance, firstborn daughters “often take on quasi-parental duties, offering their siblings direction and emotional support” (Chatterjee 4), and they “frequently internalize their jobs as caregivers as a fundamental part of who they are, which results in a strong sense of obligation and dedication to their families” (5). This is extremely similar to the experience of the able sibling as they often perform the responsibilities of the parent, caregiving for their siblings with disabilities. Kate Strohm demonstrates the behavior of the eldest daughter even though she is the youngest sibling. In her novel, she states, “As a small child I had made a decision ‘not to make waves.’ I wanted to make life easy for my parents, to make up for their pain. In many ways, I myself took on a parental role, wanting to protect and look after them” (12); thus, her position as

the able sibling influenced her in a similar way as one in the position of eldest daughter, making her susceptible to the effects of the Eldest Daughter Syndrome.

Research that delves into the Eldest Daughter Syndrome reveals greater insight into the general socio-psychological effects on younger people who take on significant caregiving roles within families. According to Deshna Chatterjee, eldest daughters experience increased levels of stress and anxiety while also struggling with an “internal conflict as they attempt to strike a balance between their responsibilities within the family and their aspirations outside of it” (5). These effects are not just present in eldest daughters, but on able siblings who often become caregivers to their other siblings who experience disability. In the book, *Living in the Land of Limbo : Fiction and Poetry About Family Caregiving*, Carol Levine writes, “most embark on [caregiving] out of love or obligation. And yet there are no maps or GPS systems to guide confused travelers” (1). Siblings who acquire the role of caregiver because of their ability in comparison to their sibling’s disability are often left out of the story. These siblings accomplish milestones together and are each other’s worst enemies and closest companions, understanding one another in ways that people outside of themselves will never fully grasp; and yet, these relationships and identities are not widely discussed in the literature of disability and family units.

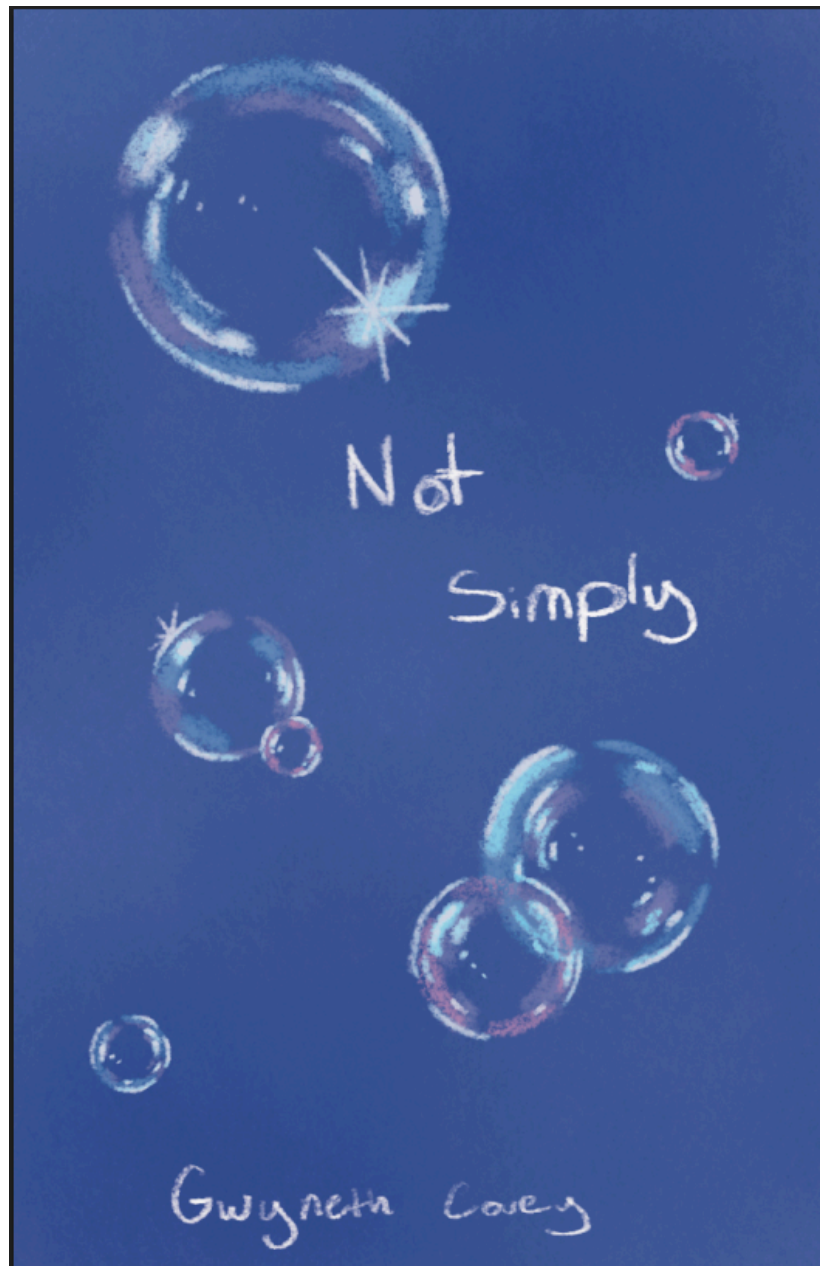
As poetry has become a popular form of expression and utilizes experimental approaches, I hope that my poetry collection will serve as an accessible and enjoyable medium to articulate my personal experience as the

eldest-able sibling and caregiver to my siblings who experience a range of intellectual and physical disabilities. Lavine states, “Poets and writers of fiction have much to say about suffering, healing, grief, and the human condition—the essence of caregiving” (2), which emphasizes poetry’s effectiveness in filling the gaps within this greater literature. There is a significant need for different representations and further exploration of experience within the literature surrounding individuals who tread the borders of disability as able siblings. With my poetry collection, I hope to keep filling this gap and serve as a friend for people on similar journeys who may feel isolated in their experiences.

Poetry Collection Outline

Cover Design

I asked Kayla Smith, an art minor and good friend, to design the cover art for my collection. The image below depicts an early draft in her creative process of the cover, which consists of the official title of the collection: Not Simply.



Draft of Book **(Redacted for copyright uses)**

The following pages display the pages as it would appear from cover to cover in print form. Pages with the inscription, “Blank Page,” would not be printed with text but are merely a representation of the book format in printed form. In its final publication form, the book’s dimensions will be 5.5 x 8.5.

Exploration of Poetry

In the section that follows, I will provide a brief analysis of a few of my poems, describing the inspiration and thematic building blocks that led to the final product. Important Disclaimer: I believe there is no wrong way to interpret poetry and any message gained by the reader is the message meant to be gained by that individual reader.

Shower Time

“Shower Time” was a poem that had been an idea floating around in my head for a very long time but I didn’t know how it would come into fruition. When the time came to write my first poem for a poetry workshop class at WOU, it gave me the forced motivation to finally create something out of it. Although the content of the poem describes an event that is routine for my siblings and I, it personally feels like a love poem. At its core, it is my love poem for my siblings and to the very act of caregiving.

Washing someone else is an intimate experience, whether it is a sexual one or not. Nakedness is the most vulnerable state a person can be in, and sharing that vulnerability in an honest and respectful way can be very powerful. My siblings are physically unable to wash themselves properly, adding another layer of vulnerability. “Shower Time” takes the reader along with my experience, including my thoughts, making myself the vulnerable one in this situation for once. I feel undressed the more one reads this poem, showing the reader the same trust my

siblings show me every time they let me wash them. It's up to the reader whether or not they participate in this experience of vulnerability, this washing of ourselves, with us on the page.

Upheaval

“Upheaval” demonstrates a deviation from my usual style of writing, and therefore, is sometimes the most confusing as it can throw the reader off. But that is the whole point as I was extremely thrown off as a young child overhearing that her brother only had a handful of years to live. Fortunately, my brother is living long after the age doctors told us he would not surpass. At present, he is healthy and will most likely live for many years to come.

With this poem, I wanted to explore how expiration dates are sometimes wrong and that either way, knowing when an edible product will expire influences how one tastes it. The poem begins with my struggle with nausea as a child. I really did vomit a considerable amount when I was younger, and it did really stop around the time that I had overheard this news about my brother. I still wonder if there was a subconscious shift in my brain that changed how my body responded to certain foods that day. It was as if, unknowingly, I told myself that I had to get myself together since my brother was going to go through something much harder than whatever I was struggling with. I never told anyone that I found out this news when I did for a very long time. It was my burning secret. In a way, this poem itself is me sharing the secret, finally releasing its spoiled nature from my body.

Friend

“Friend” was a poem that I wrote on my notes app in the wee hours of the morning when I could not fall asleep. I had just watched a reel on Instagram that featured a woman acting out what she and her sister used to pretend to play as children. While their parents thought they were playing sweetly and acting like mothers to their baby dolls, her and her sister were actually pretending a famine was occurring and argued over which baby they must eat to survive. The contrast gives a comedic look into how people often expect girls to be sweet when in reality they can also be quite vicious and harsh, even during playtime with baby dolls. It reminded me of my sister, Sydney, and I. We, too, created dramatic scenarios for our playtime adventures.

Reminiscing brought even more memories to light and I realized how normal these experiences were in relation to what my classmates talked about with each other. As a kid, I relied on this feeling of normalcy during points when I felt like I couldn’t relate to my friends. And Sydney understood this exact feeling. We relied on each other for this reason, playtime going deeper than just two kids playing games together. Looking back now, my siblings and I were always just that: normal kids. But when the pressures of our social lives at school shook this understanding, Sydney and I had each other.

The Writing Process

I have never been one to sit down and write solely for myself for extended periods of time but the days of sporadically taking ten minutes to write in my journal are long behind me now. Since starting this project, I now sporadically sit for hours circling the same thought until it pours onto the page or is washed down the drain. I had dabbled in poetry prior to working on my thesis, however, the level of dedication to the craft required for this was completely new to me. *I have no idea what I'm doing* is a daily anxiety spiral, and yet, one that did not stop me from writing. It fueled me, and for the most part, relieved me of the pressure of writing “perfectly.”

Every time I got lost in the writing process, not knowing if I was writing the end or quarter section of a poem, I reminded myself that it was okay as I was still learning. And hopefully, I never lose that because according to my research, almost every writer has doubts in regards to their “enoughness” each time they write. I found myself wanting to write every single day after beginning this project. In class, I often daydreamed about writing for hours when I got back to my apartment, changing into comfy clothes and doodling on a blank page until a piece of a phrase found me. That dream was shoved to the side when the obligations of homework, extracurricular commitments, and work persisted in its long reign at the top of my priority list. It was hard to find time for a hobby I enjoyed doing as well as maintaining a joyful writing process rather than a discouraging one.

I enrolled in an advanced poetry class, which significantly helped me learn what my writing process truly looked like and what worked best for me. For example, I discovered that I enjoy writing the most in the mornings before class and tend to produce better writing because of that. In my poetry class, I found myself gaining a great amount of inspiration from reading and listening to others' poetry. Therefore, I started reading poetry collections in any spare time I had. This not only sparked ideas for my own collection, but it also improved my writing as I learned from the poets' stylistic choices and formulaic moves. In some of these collections' pages, I have even scribbled the very first, rough lines of a few poems that made it into my own collection.

One of my greatest challenges was developing my writer's voice and style. I struggled to write many of my first drafts because I didn't like how they sounded. They just didn't sound like me in the beginning. I soon realized that I was trying to write in the way that I thought good poetry looked and sounded like. I also didn't have much practice with authentically writing in my voice as I had always taken on a more academic persona when writing literary papers. As a result, I began to cut the fluff and write out exactly what I felt and why without a filter. Then, I would start setting up my poem like a story with a beginning, middle, and end. Stories were more familiar to me as I have read countless books to my siblings so this gradual building of a scene made sense to me. It was by no means a flushed out mini narrative, just an outline of what I thought readers would need to know in order to understand what I was talking about. In addition,

understanding the importance of *showing* through my poetry instead of *telling* was what led to an outline being necessary.

“Show, don’t tell” was said to me often by Dr. Henry Hughes, my poetry professor. Early on in my writing venture, I frequently used a more direct voice within my poetry which did undermine its linguistic strength and its thematic power. With Dr. Hughes and my classmates’ help, I realized that I tended to produce single poems that were trying to do too much work. I wanted to convey many complex, interpersonal dynamics and emotions in a single poem. This is what caused my writing to lean into the *tell* aspect in hopes of catching the reader up quickly contextually rather than meaningfully. Even though the poems made sense to me, my readers were left feeling confused; thus, I began to spend time breaking my poetry down, adding the step of outlining more akin to the process of narrative writing. When I found that a scene or theme I wanted to convey was too grand, I wrote them down as ideas for longer poems or short stories.

Under the weight of these challenges, I found what helped me the most in rising above and seeing through to the end goal: verbalizing my thoughts and ideas. I discovered that I am not only an out loud thinker, but a social processor. If I am feeling unmotivated or stuck in my writing, I will talk to someone about it in order to resolve my problem. This worked almost all of the time. The person who I went to the most was one of my roommates and dear friends, Kayla Smith. After I finished a first draft of a piece of writing, sometimes even just a rough explanation of a concept, I would read it to her. The act of hearing my words spoken aloud and

under the pressure of a safe audience, allowed me to see exactly where I was lost and what I needed to do to find my way back.

Often, Kayla didn't need to say anything as the solution would strike me halfway through; however, her opinion and challenging questions always led me to writing with less worry about all the things that existed outside of my poetry. Even though every word in this project is my own, it is not just mine. Kayla very much had an active role in this project as she let me bounce ideas off of her, consoled me when I felt like I was going mad over not knowing where a concept wanted to take me, and encouraged me to keep writing when I reached the end of my threshold for positive self-talk. I would crumple under the weight of not feeling like I knew what I was doing, not being good enough, not having enough time, not having enough energy, and Kayla would pick me back up, tell me I was good enough, help me create a plan to manage my time better, and take me for much needed coffee runs.

I could say my writing process looked the same over the past two years – tie it up with a pretty bow and send it out; however, it evolved over time. But what always stayed the same was the daydreaming. I dream of the serenity from finding a creative flow or the adrenaline from fighting for the right words. I dream of trying to write as fast as my brain is forming thoughts. I dream of scribbling in the margins of poetry books. I dream of reading aloud my work to my friends and laughing with them about how bad it sounds. I dream of the warm feeling in my

chest, like my soul has been dipped in sunlight, the moment I write a draft that feels final.

Looking Ahead

This thesis project allowed me to begin working on achieving a dream that I had thought was only possible to realistically entertain in the distant future. I will forever be grateful for this opportunity, as trying as it might have been at times. I grew immensely from the experience, personally and professionally. I not only gained a newfound confidence in myself, but also in my ability to dream bigger than I have ever let myself dream before. Where there used to be blurry, abstract thoughts born of a desire I couldn't quite place, there are now clear visions of what I want. And what I want is to never stop writing for myself.

Looking ahead, I sincerely hope to publish the collection I have created for this thesis. Originally, I had planned on self publishing my collection by the end of this academic year. As I continued pouring myself into the project, I realized the pressure of a deadline was simply something I could not attach to a process. And this process was significantly influenced by a passion greater than seeing to a deadline. At the end of the day, I want to do well and I want to do right by my family and my younger self. She had great hopes for what this project could do for others and she would not have liked it if I had published it saying, "it's good enough for my thesis." I am dedicated to this project as it is more than a college thesis to me. I plan on continuing my work on this collection until I can say that it's good enough for *me*.

It might be good enough next year or in five years. In this time frame and beyond, I hope to start other projects. While working on this one, other ideas

began to stir. Whether or not they come into complete fruition, they've already started taking up space in my journal and the notes app on my phone. I have also always dreamed of writing a children's book series loosely based around one of my family members. I started working on this in the eighth grade and I've been pondering on the idea of actually finishing it for a while now. I do not anticipate that my future writing will be exempt from the events and themes I have written about in this collection as they are a part of me. I'm learning that there's simply always more to someone's story – more nuances – more bubbling thoughts – and I've only just begun to write.

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