Emerging Adult Women with Chronic Pain: A Narrative Inquiry

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Emerging Adult Women with Chronic Pain: A Narrative Inquiry

by

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It is not your responsibility to finish the work of perfecting the world, but you are not free to desist from it either.

-Rabbi Tarfon, Pirke Avot 2:21
Abstract

Women are disproportionately affected by chronic pain, yet women’s pain is frequently discounted or underestimated by medical professionals. Emerging adult women are at higher risk for insufficient pain management and face unique challenges navigating chronic illness, dating, body image, college, careers, establishing independence from family, and bearing children at an age where youth is equated to being healthy. An increasing prevalence in chronic pain has been observed across all age groups in Canada, most notably among those aged 20 to 29 with no other health conditions, yet few qualitative studies examine chronic pain exclusively in women under 30. The purpose of this narrative inquiry was to understand how the experience of living with chronic pain affects the identity of emerging adult women aged 18 to 29. Clandinin and Connelly’s (2000) form of narrative inquiry was used to explore the lived and told stories of two emerging adult women living with chronic pain, gaining a deeper understanding of how their experiences shape, and are shaped by, social, cultural, familial, and institutional narratives. Data were generated through composition of field texts that included in-depth conversational interviews and field journal writing. Participant artwork, poetry, and writing were also used for data generation and data analysis. Transitioning from field texts to research texts, narrative accounts were then co-composed with research participants. Narrative threads that resonated across narrative accounts include: silenced, invisible, and locating self with pain; pain experiences storied through relationships; and resisting the singular stories of people living with chronic pain. Personal, practical, and social significance of this work are discussed with implications for nursing practice, health education, research, and policy before concluding with final reflections.
Preface

This thesis is original, unpublished, independent work by the author, Jenise Finlay. The research reported in Chapters 4-6 were covered by Ethics Certificate number REB21-0540, issued by the University of Calgary Conjoint Health Ethics Board for the project “Young Adult Women with Chronic Pain: A Narrative Inquiry” on June 02, 2021.

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To my parents, Warren Finlay and Susan Fenske, and family, thank you for your loving support. To my husband, Chris Nixon, thank you for your unwavering love.

Dedication

This thesis is dedicated to Megan, Hailey, and all the women courageously living with chronic pain who have shared, and continue to share, their stories. Without their brave vulnerability this work would not have been possible.

In Memory

I would be remiss not to acknowledge two women whom I know would be intrigued by my master’s work. My sister-in-law, Clare Patershuk (1986-2013), was becoming a big sister to me when she was killed in 2013 by a drunk driver. Clare believed strongly in empowering other
women, and supported women impacted by sexual violence in her work as a psychologist. I regret not getting to know her better before she died, and I believe she would be proud of the work I am doing now.

Joy Finlay (1933-2021) was a remarkable grandmother and a pioneer in life who instilled in my family a determination and love of nature that has served me well. Joy supported many young women during her time as a social worker, and her interest in debating with me the ethics of contraception was unique for a woman of her generation. In preparing a speech for her memorial this past year, I rediscovered a locket she had gifted me. She had given me the locket along with another necklace in 2002, a locket she wore in high school with her uniform. With the locket was a note she wrote, “[…] I didn’t like wearing a uniform, mainly because the boys didn’t have to. […] I hope it and the locket will get some use again with you. If they could, I wonder what stories they could tell, past, present, and future.” These words have stayed with me throughout this inquiry, knowing she would have her own wonders about this work.
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Chapter 1: Introduction and Narrative Beginnings

Pain is a personal experience, intricately affected by social, biological, and psychological factors. Approximately one in five Canadians live with chronic pain, which remains a stigmatized and invalidated condition despite being the third-largest health problem worldwide (Finley et al., 2018; Green & Hart-Johnson, 2010; Pizzo, 2011; Todd et al., 2007). The estimated health care and productivity costs of chronic pain in Canada are between 56 and 60 billion dollars per year (Institute of Medicine Committee on Advancing Pain Research & Education, 2011; Wilson et al., 2015) and in 2019, one-third of Canadians with chronic pain surveyed knew someone who had taken their own life because of uncontrolled pain (Chronic Pain Association of Canada, 2019). Given the predicted increase in chronic pain prevalence because of the COVID-19 pandemic, the prevention and reduction of pain has never been more critical (Clauw et al., 2020; Mouraux et al., 2021). The prevention of pain has been declared a critical clinical issue and a focal issue to be addressed in translational pain research (International Association for the Study of Pain [IASP], 2020; Mouraux et al., 2021).

Understanding pain is regarded as one of the oldest challenges in the history of medicine (Raffaeli & Arnaudo, 2017). The impact of psychological processes on chronic pain, such as stress and reduced self-efficacy, are well-known and further influenced by sociocultural experiences (Mouraux et al., 2021). In emerging adulthood1, the importance of peer relationships and social context are heightened, particularly with chronic pain, as missed opportunities and negative peer interactions are connected to decreased psychological well-being during this developmental stage (Mouraux et al., 2021; Twiddy et al., 2017). Chronic pain

1 Emerging adulthood is defined as the developmental period between adolescence and adulthood (Arnett, 2000). In this thesis, emerging adulthood is used to refer to individuals aged 18 to 29.
across the lifespan is seen by patients and health care providers as an adversarial struggle for patients, who essay to affirm their own identity, negotiate the healthcare system, and prove legitimacy of their pain and pain needs (Toye et al., 2013). This struggle penetrates numerous levels of the person’s experience, and affirming this experience is recognized not as an adjunct, but as integral to care (Toye et al., 2013).

**Background**

Chronic pain syndromes, such as fibromyalgia, chronic fatigue syndrome, endometriosis, interstitial cystitis, vulvodynia, hypermobility syndromes, and temporomandibular disorders, either solely affect women or affect them at a rate that is at least four times higher than men (Ballweg et al., 2010; Syx et al., 2017). Research funding, training of health care professionals, awareness, and evidence-based treatments related to many of these conditions are limited (Ballweg et al., 2010). Consequently, these conditions are poorly understood, and women’s pain reports are often dismissed in health care (Kumar & Lenert, 2017; Schäfer et al., 2016; Tinkle et al., 2017; Werner & Malterud, 2003), significantly reducing quality of life and increasing the burden of chronic pain on the health care system (Green & Hart-Johnson, 2010).

Current chronic pain assessment in Canada focuses on pain intensity rather than the functional and emotional effects, despite chronic pain affecting biological, psychological, and social dimensions of well-being (Chronic Pain Task Force [CPTF], 2019; Gatchel et al., 2007). There is a recognized need to explore how pain affects certain populations differently to address the burden of pain within Canada (CPTF, 2019). Chronic pain in emerging adults is a common problem (Boulanger et al., 2007), affecting up to 30% of those aged 18 to 39 (Mills et al., 2019).

Younger age has been identified as an influencing determinant in the progression of acute to chronic pain. For example, younger age has been associated with increased likelihood of
developing post-surgical pain (Mills et al., 2019). However, beyond epidemiological or quantitative data, few studies examine chronic pain exclusively in women under 30. Prevalence estimates for Canadian women aged 18 to 25 and 26 to 35 are 16.3% and 17.3% respectively, compared to 31.5% for women aged 66 and older (Schopflocher et al., 2011), indicating there is a need to explore chronic pain in emerging adult women.

Today, women under 30 years old face mounting pressure to establish themselves financially and socially while simultaneously experiencing identity formation and pressure to have children as their fertility wanes (Klay, 2008). Most studies investigate pain related to a specific disorder (e.g., pelvic pain, cancer, fibromyalgia) (see, for example: Barnes et al., 2018; Chen et al., 2018; Gagnon et al., 2020; Malin & Littlejohn, 2012), despite recent recognition by the World Health Organization (WHO) that chronic pain is a disease in its own right (Raffaeli & Arnaudo, 2017; Treede et al., 2019). Because it can take years to receive a diagnosis for chronic pain, if at all, (Racine et al., 2014; Syx et al., 2017), more studies are needed that explore the experience of chronic pain in emerging adult women unspecific to diagnosis. Early identification and intervention may interrupt a trajectory towards chronic pain (Tan et al., 2019), improving quality of life for emerging adult women and reducing costs to the health care system.

Experiences of accessing health care comprise prevalent narratives in the findings of this thesis, with stories of social and physical spaces of living with pain shaping the identity of participants. Using Clandinin and Connelly’s (2000) narrative inquiry methodology, I explore the experience of living with chronic pain in two emerging adult women, examining the dominant social, cultural, and institutional narratives (Clandinin, 2006) that influence and shape health of this demographic.

**Defining Chronic Pain**
Pain is an “unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (Raja et al., 2020, p. 1). Chronic pain has been defined in the literature as pain persisting or recurring beyond normal healing time, typically either three months or six months in minimum duration (IASP, 2018; Treede et al., 2015). The traditional definition of chronic pain most often describes *chronic secondary pain* when pain occurs from an underlying condition and continues after treatment of a condition (Treede et al., 2019). In contrast, *chronic primary pain* refers to pain that cannot be better explained by another diagnosis (Nicholas et al., 2019). The IASP (2018) has suggested a simpler definition of chronic pain, “pain that persists for a given length of time” (p. 4), to recognize significant variation in healing time and syndromes associated with chronic pain where normal healing does not occur.

**Defining Emerging Adulthood**

While the age range for emerging adults varies in the literature, most chronic pain studies in emerging adults utilize an age range of 18 to 30. Emerging adulthood as a developmental stage is a more recent categorization, referring to the time between adolescence and adulthood, as research indicates many 18- to 25-year-olds do not consider themselves adults (Arnett, 2000; Brown et al., 2021; Nelson & Barry, 2005). The term *emerging adulthood* is sometimes used interchangeably with *young adulthood* and characterizes a unique period of identity exploration and transition, with emerging adults facing increased responsibility as they mature and attain increasing independence (Arnett, 2000). Additional challenges exist for emerging adults living with chronic illness, such as transitioning from pediatric to adult care (Stinson et al., 2013). Furthermore, cognitive executive functioning skills for self-management are not considered fully developed until the mid-to-late twenties (Stinson et al., 2013). Pain in childhood and adolescence can have negative effects on development and lead to increased risk for chronic
pain, substance use, and psychological disorders (Groenewald & Palermo, 2019). Additionally, emerging adults with chronic pain may be more vulnerable to challenges during this time; yet, the majority of adult chronic pain research focuses on those middle-aged and older (Brown et al., 2021). In my nursing practice, I have found myself drawn to caring for women in the developmental phase of emerging adulthood.

**Locating Myself in the Narrative Inquiry: Narrative Beginnings**

My passion for women’s health was ignited when I began working in postnatal and sexual health care as a rural public health nurse in northern Alberta. It was in this position that I began to see the influence of social determinants of health on chronic and unmanaged pain, and the interconnections between mental health, history of abuse or trauma, substance abuse, and stigma. I eventually transitioned from rural public health nursing to Edmonton’s Healthy Beginnings program, serving a region in northeast Edmonton with many new Canadians, Indigenous peoples, and individuals of low socioeconomic status.

My passion for working with emerging adult women grew further when I started working at Edmonton’s Birth Control Centre. This clinic primarily serves women and emerging adults that experience barriers to accessing reproductive health care. Over time at the clinic, I met more patients with pain diagnoses (whether pelvic pain or otherwise), mainly women under 30. Recurring themes emerged from conversations with these patients. I began to see dismissal as a common complaint: dismissal from health care providers not believing their pain was real or dismissing them as “too young” or “too healthy looking” to have chronic pain. Emerging adult women reported having their pain dismissed by doctors as a mental health issue, often due to misinterpretation or inadequate assessment. The women I encountered expressed frustration about not having a diagnosis related to their pain, and a lack of services tailored to their unique needs as emerging adult women. The more I spent time with emerging adult women living with
invisible chronic pain, the more I identified there is a lack of awareness among society and health care providers on this population, and the inequities experienced by emerging adult women with chronic pain became part of my research puzzle\(^2\) (Clandinin & Connelly, 2000).

As these women described experiences of discrimination due to mental health, trauma, addictions, disability, or complex illness, I began to reflect on how some of them told me I was the first person they felt they could tell their experiences to without judgement. I wondered how their experience of physical pain affected their identity as women transitioning into adulthood. More specifically, I was curious about the effect of pain on body image and sexuality in the context of trauma, adversity, and marginalization. As I transitioned professionally into my current role with the provincial sexually transmitted infection program, my wonders\(^3\) (Clandinin & Connelly, 2000) continued. In my current professional work as a clinical lead liaison, sexual health specialist, and partner notification nurse, I work primarily with women under 30, some of whom are involved in survival sex (the exchange of sex for essential basic needs). As a result of my nursing practice, I have become more interested in the complex interrelation between trauma, chronic pain, sexuality, and identity, leading me to this area of research: my research puzzle pertains to how the experience of living with chronic pain affects the identity of emerging adult women. My narrative beginnings as a registered nurse unfolded simultaneously to my own experience navigating chronic pain.

**Personal, Practical, and Social Justifications for this Research**

A large component of my personal justification for this study, which drives much of my passion and dedication to my professional work, is based on my own experience with chronic

\(^2\) In narrative inquiry, the term research puzzle is used instead of research question to reflect the evolving nature of understanding experience throughout the inquiry.

\(^3\) Wonders refer to questions that are both generated from and inform the personal, practical, and social justifications of the narrative inquiry.
pain. I have lived with chronic pain since age 14; after 15 years of living with chronic pain, I was diagnosed with hypermobile Ehlers-Danlos syndrome. Hypermobile Ehlers-Danlos syndrome is an hereditary connective tissue disorder associated with numerous musculoskeletal complaints and typically worsens with age (Tinkle et al., 2017). While knowing my diagnosis means I can better advocate for treatment, there is no cure for hypermobile Ehlers-Danlos syndrome; I face a lifetime of surgeries and worsening pain, which has raised many questions for me around my past, present, and future identity. The diagnostic odyssey I endured has shaped who I am as a nurse, researcher, wife, friend, musician, and outdoor athlete.

At age 22, when my sixth family doctor responded to my plea for an explanation for the worsening pain with, “How about fibromyalgia?”, I did not question his diagnosis. Instead, I mentally refused to add fibromyalgia to my ever-increasing number of medical labels; at the time, I only knew that fibromyalgia was viewed as an excuse for laziness and a fibromyalgia diagnosis would ensure I was seen differently. After enough contradicting medical opinions, I started to give up on finding an explanation for the pain. Perhaps some of the medical providers were right, and the pain was from trauma I endured as an adolescent. Perhaps nothing could be done. Perhaps I was too active, or not active enough, or because I looked healthy (as I was told by more than one physician), the pain was purely psychological. Other physicians told me I was not “depressed enough” to have fibromyalgia, and I felt penalized for maintaining a high level of functioning despite my pain.

My care was fragmented by body part, the number of specialists multiplied as I accumulated issues: psychiatry, podiatry, rheumatology, plastics, orthopedics, sports medicine, hand therapy, occupational therapy, physiotherapy, gynecology, nutrition, dermatology, psychology, and psychiatry. At one point in my life, living alone while juggling an overwhelming number of medical appointments, daily physiotherapy, full-time work, school,
relationships, and the demands of daily life when none of my friends could relate was both exhausting and isolating.

After fifteen years of seeking an explanation for the pain, the relief in having a clinical diagnosis of Ehlers-Danlos was immense. Looking back now, many of my experiences accessing health care mirrored those of the women I cared for in my nursing practice, and my tortuous journey to a medically recognized cause of musculoskeletal pain is more common than I once thought. I was not alone, although I felt like it. Now, each time I explain my research to someone, I am nearly always offered a story similar to mine – either theirs, or someone they know. In my experience, many women cannot quite advocate or articulate their pain to get the right treatment, and this was my story for many years.

As I leave emerging adulthood, I feel privileged to consider myself remarkably high functioning, having acquired the knowledge and skills to advocate for myself. Even now, when I see a new care provider, I am often asked, “what’s that?” , despite hypermobile Ehlers-Danlos being the most common inherited genetic connective tissue disorder worldwide (Tinkle et al., 2017). I have grown weary of staying silent, knowing I will be seen differently if I disclose a chronic pain diagnosis. As I help others advocate for themselves and navigate their own diagnostic journey, I feel compelled to publish some of their stories, told and re-told, and shaped by my own. These experiences inform the practical and social justifications for doing this work. My condition continues to evolve, as do I. In making visible this narrative inquiry, I hope to increase awareness of emerging adult women living with chronic pain who have been underserved and experience marginalization in accessing care.

**Conclusion**

In the chapters that follow, I describe the landscape of chronic pain and the narrative inquiry study I undertook to explore that landscape alongside two emerging adult women
participants. I use Clandinin and Connelly’s (2000) form of narrative inquiry to understand how the experiences of living with chronic pain shapes, and has been shaped by, Megan⁴ and Hailey⁴. Through coming alongside Megan and Hailey, past, present, and future stories of living with pain emerged. These experiences were storied by place, time, and social context with individual pain and disability storied through family and romantic relationships. Following Hailey and Megan’s narrative accounts, three narrative threads are explored in this thesis, beginning with experiences of dismissal by family, health care providers, and the self. Both Megan and Hailey resist dominant narratives, defying many of the norms assumed of emerging adult women living with chronic pain.

⁴ Pseudonyms chosen and used with permission from the participants.
Chapter 2: Literature Review: The Landscape of Chronic Pain

In this chapter, I provide an overview of relevant literature on chronic pain in all ages as well as chronic pain in women, emerging adults, and emerging adult women. To provide context, I summarize chronic pain prevalence and epidemiology followed by a summary of differences in pain based on sex. How chronic pain patients experience health care is significant to the quality of life of chronic pain patients, and I highlight prominent findings in the literature. Finally, I discuss what is known about emerging adult women living with chronic pain in addition to themes in the literature on the lived experience of chronic pain.

It is difficult to determine the prevalence of chronic pain in Canada let alone worldwide, as population surveys vary due to differences in chronic pain definitions and study methodologies. The most recent population survey in Canada is from 2011 and found that 18.9% of Canadians live with chronic pain, with 50% of those having lived with it for more than 10 years (Reitsma et al., 2011; Schopflocher et al., 2011).

Prevalence of pain is influenced by social determinants of health. Occurrence and severity of chronic pain is typically higher in populations most affected by discrimination, poverty, or social inequities, including Indigenous peoples, some ethnicities, and women (Allan & Smylie, 2015; Pizzo, 2011). For women, pain severity and chronic pain rates are higher across all age groups when compared to men, and women are at greater risk of developing chronic pain (Bartley & Fillingim, 2013; Racine et al., 2014; Schopflocher et al., 2011; Umeda & Kim, 2019). Additionally, sexual orientation may play a role in the development of chronic pain due to marginalization, as bisexual women and lesbians are at greater risk than heterosexual women for certain chronic illnesses such as arthritis (Fredriksen-Goldsen et al., 2012).

Social determinants of health such as gender have a large influence on the risk for chronic and unmanaged pain. In addition, the interplay between chronic pain, mental health, history of
abuse or trauma, substance abuse, and stigma is complex (Holley et al., 2013; Iversen et al. 2017; Okifuji & Hare, 2015; St. Marie, 2016; Tan et al., 2019). Previous abuse or trauma increases risk for chronic pain; however, current chronic pain assessment in Canada is focused on pain intensity rather than the functional and emotional effects, despite chronic pain affecting biological, psychological, and social dimensions of well-being (CPTF, 2019; Gatchel et al., 2007).

The effects of chronic pain on well-being are extensive. As a subjective and highly individual experience, pain is multi-dimensional and affects all aspects of functioning (Keponen & Kielhofner, 2009). Chronic pain remains stigmatized and invalidated, despite recognition as a disease itself, with inadequate treatment being a global issue (CPTF, 2019). Other than direct health care costs, pain interferes with one’s ability to function and participate in workplaces, relationships, schools, and society (Boulanger et al., 2007; Pizzo, 2011; Racine et al., 2014). When not controlled, chronic pain can lead to severe stress, depression, and isolation (Tinkle et al., 2017; Ziadni et al., 2018).

**Differences in Pain Based on Sex**

The impact of chronic pain on social and physical functioning is further affected by differences in pain based on sex. Most chronic pain syndromes are prevalent in women at a rate much higher than men (Ballweg et al., 2010; Malin & Littlejohn, 2012). Consequently, women present with greater pain-related disability and utilization of health care, as well as pain of greater severity, duration, and frequency (Plesh et al., 2002; Tinkle et al., 2017). While those

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5 Sex (i.e., female) and gender (i.e., woman) are often used interchangeably; however, sex and gender have different meanings (Canadian Institutes of Health Research, 2020). For this study, I use the term women to describe individuals who were born female at birth and whose gender matches this assignment.
with chronic pain often have anxiety, rates of anxiety are higher in women and is associated with greater pain intensity (Sim et al., 2019). Women’s pain is frequently discounted or underestimated by medical professionals and as many as 50 million women in the United States live with a chronic pain condition that is not well understood (Ballweg et al., 2010; Schäfer et al., 2016).

Along with differing experiences accessing health care, responses to pain itself vary based on sex. While it is still unclear why chronic pain prevalence is higher in women than men, studies have found both biological and psychosocial differences in how men and women respond to identical types of pain (Mogil, 2012; Racine et al., 2014). Biologically, women have been found to demonstrate increased sensitivity to painful stimuli and less efficient pain inhibitory processing, which may contribute to increased risk for chronic pain (Racine et al., 2014). Furthermore, there are differences in how women respond to pharmacologic and non-pharmacologic pain interventions; some studies indicate acceptance-based and multimodal pain management programs are more effective in women (Keogh, Bond, et al., 2005; Keogh, McCracken, et al., 2005; Pieh et al., 2012), although the effects may not be as long-lasting in women compared to men (Keogh, McCracken, et al., 2005).

Additionally, women may experience greater side effects related to opioid use and increased analgesic effects in patient-controlled opioid analgesia (Fillingim et al., 2009; Fillingim et al., 2005; Holdcroft, 2006; Miaskowski et al., 2000). However, the literature appears to be inconsistent as to whether women consume and are prescribed more or less analgesics than men, and further research is needed on biological differences in response to pain interventions (Bartley & Fillingim, 2013; Holdcroft, 2006; Miaskowski et al., 2000; Pieretti et al., 2016). Gender differences in pain may also be influenced by sex hormones, genotype,
cognition, affective states, body size, gender roles, and occupation tendencies (Mogil, 2012; Racine et al., 2014).

Psychosocially, women may also cope differently with chronic pain than men (Racine et al., 2014). Stress exposure early in life may explain some differences in how women convey and experience pain, as childhood or early life abuse has been associated with adult chronic pain (Bartley & Fillingim, 2013). Previous childhood abuse has also been linked to decreased pain sensitivity, especially in women (Fillingim & Edwards, 2005). These differing responses to chronic pain can affect overall health by affecting activity levels, disability rates, and capacity to socialize (Sturgeon & Zautra, 2010). The complexity of chronic pain is a challenge for both health care professionals and women living with it, as indicated by the impact of chronic pain and an increasing need for further research on women’s experiences.

**Accessing Health Care**

Chronic and medically unexplained pain disorders are complex, challenging the medical system and health care providers, who receive little training on pain conditions that predominantly or only affect women (Werner & Malterud, 2003). Care for and research into medically unexplained chronic pain conditions have historically been underfunded compared to other medical conditions (Ballweg et al., 2010; Green & Hart-Johnson, 2010). As a result, physicians find these conditions difficult to manage, and must handle distrust and frustration from patients navigating the health care system.

Women with chronic pain report a greater number of health problems, complex symptoms, mental health and/or long-term symptoms than men (Ballweg et al., 2010; Schäfer, Prkachin, Kaseweter, & Williams, 2016; Werner et al., 2004). Both patient and provider characteristics influence existing gender bias in the health care system (Bartley & Fillingim, 2013), and conditions where pain is the only reported symptom predominantly affect women
(Samulowitz et al., 2018). These “medically unexplained” conditions are associated with disbelief of women’s pain (Samulowitz et al., 2018). Consequently, women are more likely to be dismissed and their pain labeled as “emotional, psychogenic, hysterical, or oversensitive” (Ballweg et al., 2010, p. 4). Because of these biases, women with chronic pain struggle for credibility and must display significant determination to receive investigation and treatment, in addition to coping with chronic pain (Werner et al., 2004; Werner et al., 2003). Chronic pain conditions in women are more likely to go undiagnosed and inadequately controlled; women experience a greater delay in diagnosis than men. For example, the average delay in Ehlers-Danlos syndrome diagnosis in women is 16 years, compared to four years in men (Ballweg et al., 2010; Syx et al., 2017). As a result of negative health care experiences, notable anger, frustration, and mistrust toward the health care system can occur (Lavie-Ajayi et al., 2012).

**Emerging Adult Women**

Studies into pain in emerging adult women are few, despite differences in the pain experiences based on sex and developmental stage (Feinstein et al., 2017). Two notable gaps in the literature on emerging adults who experience chronic pain are body image and sexuality. While two studies acknowledge the importance of discussing and understanding sexual relationships in emerging adult women with chronic pain (Stinson et al., 2013; Werner & Malterud, 2003), I am aware of no studies that explored the concept of sexuality with participants⁶. Body image, an important issue to those living with chronic pain, especially among emerging adult women (Snelgrove & Liossi, 2009; Stinson et al., 2013), was also not investigated with participants in the literature reviewed.

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⁶ At the writing of this thesis.
Despite comprising a primary demographic for many illnesses, emerging adult women with chronic pain are an underserviced and under-researched population. Unfortunately, emerging adult women are at higher risk in primary care for insufficient pain management (Green & Hart-Johnson, 2010), facing unique challenges navigating chronic illness, dating, body image, college, careers, establishing independence from family, and bearing children at an age where youth is equated to being healthy (Hirsch, 2018; Stinson et al., 2013).

**Overarching Themes in the Literature**

The storied landscape of pain appears to be primarily quantitative in nature, focusing on the measurable aspects of pain rather than the subjective experience of pain. Qualitative research is valuable in understanding the lived experience of a population, yet of the six studies that met inclusion criteria and explored chronic pain exclusively in emerging adult women (Barnes et al., 2018; Beal et al., 2020; Gagnon & Elgendy, 2020; Gansky & Plesh, 2007; Malin & Littlejohn, 2012; Plesh et al., 2002), only one had a qualitative design (Barnes et al., 2018). Several studies illustrated the lived experiences of chronic pain in either women, emerging adults, or the general chronic pain population. To my knowledge, there are no studies that examine the experiences of chronic pain using Clandinin and Connelly’s (2000) form of narrative inquiry, and few studies use a qualitative design to understand chronic pain exclusively in emerging adult women.

The literature depicts a universal struggle for credibility and recognition in living with chronic pain, more so among women, indicating dominant narratives of women with pain as exaggerating or feeble (Keponen & Kielhofner, 2009; Lavie-Ajayi et al., 2012; Snelgrove & Liossi, 2009; Werner & Malterud, 2003). Patients’ narratives illustrate a delicate balance between showing pain to justify its existence and hiding pain to avoid stigmatization; emerging adult women describe fears of being perceived as malingering and this need to appear as a
credible patient is an ongoing burden to patients of all ages (Barnes et al., 2018; Keponen & Kielhofner, 2009; Lavie-Ajayi et al., 2012; Skuladottir & Halldorsdottir, 2008, 2011; Toye et al., 2013; Werner and Malterud, 2003). Lavie-Ajayi et al. (2012) referred to this as *narratological distress*, where it becomes difficult to trust one’s bodily experience and feelings when portraying the role of credible patient. Since emerging adults are storied as healthy, dismissal of and disbelief about chronic pain from friends, family, and health care providers are stigmatizing and can lead to shame, self-blame, and demoralization (Bernhofer et al., 2017; Carter et al., 2002; Carter et al., 2013; Werner & Malterud, 2003).

Despite experiencing demoralization from dismissal in health care encounters, patients maintain a strictly medical or physical stance in their illness narratives until credibility of pain has been established (Werner & Malterud, 2003). Having a diagnosis for chronic pain is important to patients to establish credibility, as disbelief from others affects self-esteem, integrity, and dignity (Steinhaug et al., 2002; Werner et al., 2004; Werner & Malterud, 2003). With a lack of external understanding and support, isolation results, in addition to reduced physical and cognitive functioning. Furthermore, social isolation can arise from fear of stigmatization and fear of being a burden to others (Bernhofer et al.; Keponen & Kielhofner, 2009; Kowal et al., 2012).

Dichotomies, where two contradicting experiences or concepts occur simultaneously, are prevalent in chronic pain patient narratives. These include dichotomies between the past and present, ideal self and perceived self, and a dichotomy in the fight for credibility in pain while not seeming too weak or oversensitive (Snelgrove & Liossi, 2009; Werner & Malterud, 2003).

To cope with the challenges of chronic pain, finding meaning in suffering and affirming a sense of self are important to patients, despite this method of coping being an additional challenge (Skuladottir & Halldorsdottir, 2008; Werner & Malterud, 2003; Werner et al., 2003).
Bury’s (1982) theory of *biographical disruption* is used in the literature to describe this need to create meaning from illness to cope with the disruptive nature chronic pain plays in all aspects of one’s life (Lavie-Ajayi et al., 2012), likely shaping the ways in which individuals living with chronic pain story themselves.

One main challenge evident in living with chronic pain is maintaining a sense of control over the pain and self (Skuladottir & Halldorsdottir, 2008). Because of the totality of chronic pain, grieving is a large part of living with chronic pain; for emerging adults, this includes narratives of future loss because of thwarted opportunities (Twiddy et al., 2017). Grieving is associated with loss of control over one’s life, loss of identity (both past and future), loss of meaning in life, and a diminished sense of self (Skuladottir & Halldorsdottir, 2008; Snelgrove & Liossi, 2009). Accepting uncertainty assists in maintaining some sense of control by accepting the unpredictability of pain and the future (Kratz et al., 2007; Ramírez-Maestre & Esteve, 2014; Vallejo et al., 2020; Werner et al., 2003). By retaining a sense of control, feelings of demoralization can be reduced (Skuladottir & Halldorsdottir, 2008). More recent research is needed on the challenges and adaptive coping mechanisms of living with chronic pain; overall, it is evident that more research is needed on the experiences of emerging adult women living with chronic pain.

**Conclusion**

As a complex and highly individual experience, chronic pain represents an enormous individual and societal burden despite recognition as a disease in its own right (IAASP, 2018). The impact of chronic pain on individual quality of life is often detrimental (CPTF, 2019). Due to its complexity, understanding chronic pain is a challenge for patients and providers alike. Additionally, populations most impacted by chronic pain are those affected by marginalization and inequities. This includes women, who are more likely to remain undiagnosed, be incorrectly
diagnosed, receive inadequate treatment, and experience demoralization and dismissal of their pain (Mills et al., 2019; Nicholas et al., 2019; Samulowitz et al., 2018).

Still, an increasing prevalence in chronic pain has been observed across all age groups in Canada, most notably among those aged 20 to 29 with no other health conditions, with rates of chronic and unmanaged pain expected to drastically increase due to COVID-19 (Clauw et al., 2020; Lacasse et al., 2021; Schopflocher et al., 2011). Individuals in emerging adulthood are particularly vulnerable to the impacts of chronic pain, and face additional challenges living with chronic illness (Brown et al., 2021). Pain in emerging adulthood can have negative effects on development and increases risk for substance use and psychological disorders (Groenewald & Palermo, 2019). Furthermore, in women of child-bearing age, unmanaged chronic pain can incur long-term consequences on infant and childhood development (Wilson & Fales, 2015). Despite this, research on the chronic pain experiences of emerging adults, women, and emerging adult women is lacking. Chronic pain in emerging adult women is not rare or unusual, but vastly under recognized.
Chapter 3: Research Design

Stories shape our reality. They help us make sense of our pasts, what we’ve been through, who we were then, who we are now, and who we would like to be going forward.

- Esther Perel, *Letters from Esther #23*

**Narrative Inquiry**

Using Clandinin and Connelly’s (2000) methodology of narrative inquiry, I explore the experiences of two Canadian women aged 18 to 29 living with chronic, non-malignant pain. As the affective-emotional aspect of chronic pain is highly personal (Barnes et al., 2018; Smith & Sparkes, 2009), narrative inquiry is a valuable methodology to understand the complex experience of living with chronic pain. By understanding how participants make sense of their experiences through stories, narrative inquiry assists in understanding how the experience of chronic pain has shaped, and continues to shape, the identity of emerging adult women.

Experiences told through stories can help to understand how individuals make sense of their illness. The stories of those experiencing pain, illness, or disability are often not heard without alteration or fragmentation by researchers; through stories, the narrative identity of participants can be understood since narrative inquiry allows participants to share their experiences (emotional and physical) without dissection (Holloway & Freshwater, 2007). My inquiry examines how participants’ identities have evolved over time in the context of place, social interaction, and social landscapes using Clandinin and Connelly’s (2000) conceptual framework of the *three-dimensional narrative inquiry space*.

To understand experience, the three-dimensional narrative inquiry space is used. The three-dimensional narrative inquiry space comprises three commonplaces central to the inquiry: time/continuity (the dimension of past, present, and future), sociality/interaction (the personal and social dimension), and place (the dimension of place/situation) (Clandinin & Connelly, 2000; Clandinin et al., 2007; Connelly & Clandinin, 2006; Green, 2013). As the researcher, I
am situated in these dimensions throughout the process of inquiry, working with participants to understand the influences of time, sociality, and place in their narrative (Clandinin & Connelly, 2000). This framework is important during analysis to understand how experiences have been shaped (Wang & Geale, 2015) and all three elements are explored simultaneously during narrative inquiry (Green, 2013).

As I prepared for my inquiry, I examined how my knowledge of emerging adult women with chronic pain resonates with my own experiences, both personally and professionally. I began to situate myself alongside the participants, shifting from thinking about stories to thinking with stories (Morris, 2001). By thinking with stories instead of about them, the impact of emotional experiences is given room to resonate with audiences (Morris, 2001). Thinking with stories allows narratives to work on the researcher, rather than the researcher working on stories by viewing narratives as a detached, rational object to be formulaically modified (Morris, 2001). The stories of participants have become enmeshed in some of my own stories, shaping who I am by shifting some of my perspectives and encouraging me to revisit my own experiences as I make sense of participant stories in relation to mine. In situating myself alongside participants as the researcher, I committed as a collaborator in relational research, becoming an inseparable part of the landscape of inquiry into emerging adult women’s experiences of chronic pain.

**Philosophical Foundations of Narrative Inquiry**

The philosophical foundation for narrative inquiry draws on the work of John Dewey. John Dewey was an American philosopher whose pragmatic ontology of experience acted as a theoretical framework for understanding narrative experience (Clandinin, 2016; Dewey, 1938), and his pragmatism centered on improving human experiences (Legg & Hookway, 2020). In other words, Dewey viewed experience as something to be understood practically through
relational and participatory ways (Clandinin & Caine, 2013). Translated into narrative inquiry, experience is seen as knowledge by understanding how individual experiences are expressed, shaped, and enacted through time, place, and social interaction (Clandinin & Caine, 2013).

Epistemology, or way of knowing, can vary based on the methodology used. Dewey’s epistemology focused on inquiry as a process of productive knowledge-seeking, viewing science and philosophy as embedded within cultural contexts (Hickman et al., 2009). Clandinin and Connelly (2000) reflect Dewey’s view of experience: “People are individuals and need to be understood as such, but they cannot be understood only as individuals. They are always in relation, always in a social context” (Clandinin & Connelly, 2000, p. 2). To understand and study experience in narrative inquiry, it is done narratively, and stories are retold by individuals to generate data for narrative inquiry research while understanding the influence of social landscapes (Clandinin & Caine, 2013).

How chronic pain is understood is highly contextual. Understanding how social landscapes enable or constrain the individual is an important aspect to analyzing and interpreting in narrative inquiry (Bloomberg & Volpe, 2018), as well as chronic pain. Dewey (1938) wrote of interaction and continuity as two criteria for experience. His concept of interaction dictates people can only be understood as individuals in a social context, while continuity refers to the idea that experiences lead to further experiences (Clandinin & Connelly, 2000). Regardless of where the narrator positions themself in time (past, present, or future), there is always past experience that leads to future experiences (Clandinin & Connelly, 2000). Dewey’s theory of experience influenced narrative inquiry in its emphasis on researcher-participant collaboration in the context of time, sociality, and place (Clandinin & Connelly, 2000).
In narrative inquiry, experience is understood as a social phenomenon. As such, the researcher-participant relationship is central to narrative inquiry (Clandinin & Connelly, 2000). Participants share and trust the researcher when entrusting them their stories, collaborating with the researcher to facilitate the co-creation of narratives (Bloomberg & Volpe, 2018; Clandinin & Connelly, 2000). This inquirer-participant relationship is part of the social dimension of Connelly and Clandinin’s (2000) three-dimensional inquiry space (Clandinin et al., 2007). It is through the lens of the researcher-participant relationship that the researcher queries and studies the participants’ experience told by story (Bloomberg & Volpe, 2018). The relationship between researcher and participant is central to the inquiry, as is recognizing the worth of stories that participants share (Bloomberg & Volpe, 2018). Narrative researchers play a dual role as both researcher and participant as they collaborate with the participant in an evolving process of co-creation. Participants play an active role in the research process, and validation checks are done throughout data collection and analysis to negotiate the meaning of stories (Wang & Geale, 2015). The fundamental relational aspect of inquiry means that narrative inquirers situate themselves in a shared research space with the participant, “living alongside in the living and telling of stories” and becoming part of the storied landscape under study (Clandinin, 2016, p. 30).

**Methods**

To understand the experiences of emerging adult women with chronic pain narratively, research methods and procedures according to Clandinin and Connelly’s (2000) form of narrative inquiry were followed. Here, I will describe how I completed participant recruitment, data generation, and data analysis, and addressed some of the ethical considerations of undertaking this research.

**Participants and Recruitment**
Purposive sampling was used to recruit participants and screen for inclusion criteria. Narrative inquiry uses a small number of participants to allow for multiple, in-depth conversational interviews with each participant (Clandinin, 2007; Kim, 2015). Inclusion criteria were as follows: aged 18 to 29, female sex and identifying as a woman, self-report living with persistent non-malignant pain for greater than three months duration at the time of recruitment, speaks English, has sought health care related to the pain, and able to provide informed consent for study participation. Participants were not excluded if they had not yet been diagnosed with a pain condition or underlying health condition that is associated with pain. Exclusion criteria included: experiencing malignant pain, lack of capacity to provide informed consent, and inability to communicate in English. Because I only speak the English language and did not have the resources to include non-English speakers, participants needed to be English speakers.

As part of the inclusion criteria, I chose an age range of 18 to 29 for my sample to identify the experiences of women in emerging adulthood. Emerging adulthood and adolescence are developmental stages that overlap, since adolescence is defined as age 10 to 19 (Arnett, 2000). The exclusion of participants over age 29 was chosen to align with the age range used in most emerging adult studies, and because turning 30 is often significant to women as they transition to middle adulthood roles and a new decade in life (Reynolds, 2013).

Recruitment of emerging adult women that met the inclusion criteria was done through three rehabilitation and wellness clinics in Calgary in addition to the University of Calgary’s research recruitment website7. Using postcard-sized flyers (Appendix A), recruitment was conducted through community partners and word-of-mouth from practitioners at these clinics.

7 https://www.ucalgary.ca/research/participate/.
Between June and December 2021, approximately 37 women responded to recruitment advertising. At the beginning of recruitment, after expressing initial interest in participation, only three participants responded to subsequent emails. Subsequent women who responded to recruitment advertising were advised the study was full and asked if they wished to be contacted if recruitment re-opened. In total, three participants were provided detailed study information and gave informed consent. Of these three, one participant was lost to follow up after providing informed consent. Two participants, Megan and Hailey, engaged in the study from beginning to end, within the relational inquiry space.

Data Generation

Data generation, or collection, with Megan and Hailey was conducted within the relational inquiry space. Four in-depth conversational interviews, each lasting one to two hours, with each participant were the primary method of data generation. Meetings with participants were held virtually due to current public health measures during the COVID-19 pandemic; virtual meetings were held using Zoom via a University of Calgary licensed Zoom account. Participants’ artwork, pain journals, poetry, and researcher-created annals were also used as study artifacts (Clandinin, 2016). One participant, Megan, provided her clinic records and consented to the use of these as study artifacts. Artifacts in narrative inquiry are artwork, photographs, documents, and other memorabilia that represents past participant experiences (Clandinin, 2016). An annal is a timeline of important life events or experiences and is used in narrative inquiry to help understand past experiences, possibly elucidating further experiences (Clandinin, 2016). I created visual annals for each participant based on life events storied during our conversational interviews. These annals were reviewed with each participant to create a visual representation of stories told over the participant’s recollection of time. Using Zoom screen-sharing, I edited the annal in live time with the participant to create more of a sense of
co-creation, or joint ownership. The annals also acted as a prompt for additional storytelling and clarification of significant events.

Annals were used as part of study data in addition to texts and other artifacts. In narrative inquiry, data are referred to as *field texts* (Clandinin, 2016). Field texts include field notes or journals, interview transcripts, emails, telephone conversations, photographs, essays, and artwork that reflect the experiences of the participant and/or researcher. Conversational interviews were conducted via Zoom. Interviews and ongoing communication with participants via email was primarily conducted over a period of two months. Follow up communication with participants occurred until narrative accounts were approved by participants and finalized approximately six months after initiation of data generation.

As part of data generation, all interviews were recorded and transcribed, and artifacts were photographed and emailed by participants for analysis. I kept a field journal to critically reflect on my experiences alongside each participant and encourage reflexivity (Kim, 2015; Nasheeda et al., 2019). In narrative inquiry, transitioning field texts to *research texts* through analysis is an evolving, reflective process where the researcher searches for meaning and understanding of field texts in relation to the research puzzle (Clandinin, 2016; dela Cruz, 2014). In the case of this study, research texts are the retelling and discussion of Megan and Hailey’s experiences, and this master’s thesis is considered a *final research text*.

**Data Analysis and Composing Research Texts**

To shape interim research texts into final research texts, interview transcripts were analyzed. Data analysis was done using McLeod and Lynch’s (2000) three-stage method of interpretation for guidance, as identified in Clandinin’s (2007) *Handbook of Narrative Inquiry: Mapping a Methodology*. This method focuses on analyzing stories as a whole, primary unit (McLeod & Lynch, 2000). Interview transcripts were read and reread successively to identify
significant relationships, places, and periods of time. Methods described in Clandinin’s (2016) book, *Engaging in Narrative Inquiry*, were also used to ensure interpretation remained consistent with the tenets of Connelly and Clandinin’s narrative inquiry methodology, viewing storied experience as a source of knowledge and understood in the context of the three-dimensional inquiry space (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990, 2006).

To verify my understanding of the participants’ storied experience within the three-dimensional inquiry space, participants were involved throughout the process of shaping research texts. *Interim research texts* were used to engage participants in follow-up interviews, verify interpretation of their narratives, and led to generating more field texts as needed to ensure authenticity (Clandinin, 2016). Stories were formed and retold from interview transcripts and other field texts like field notes, photographs, and journals (Clandinin & Caine, 2013; Nasheeda et al., 2019). Participants’ artifacts were included in the analysis, as was my field journal. Recognizing the co-creation of stories as a collaboration between the participant and researcher, my field journal notes were used to assist in interpretation of narrative meanings. *Restorying* is the process of analyzing key elements (characters, main events, settings, and character positioning) of the story, then reorganizing and rewriting them (Clandinin & Connelly, 2000; Nasheeda et al., 2019). This was done in negotiation with participants to identify and interpret shared experiences, paying close attention to how the narratives were situated in time, sociality, and place.

When restorying key elements, narrative meanings were analyzed with feedback from participants. The entire story and its meaning was interpreted, focusing on story content and its relation to the three-dimensional narrative inquiry space to deepen understanding of experiences (Clandinin & Caine, 2013). Main statements were identified to represent a narrated experience (Clandinin & Caine, 2013). After retelling each participant’s narrative account (Chapter 4 and
I reread transcripts and narrative accounts again, using the three-dimensional narrative inquiry space to identify narrative threads that resonated across participant narrative accounts (Clandinin, 2007; McLeod & Lynch, 2000). *Narrative threads*, also known as *resonant threads*, are central narratives or patterns that reverberate across individual narrative accounts (Clandinin et al., 2019), and three main narrative threads were chosen for further analysis in the present study.

**Stories, Narratives, Narrative Accounts, and Storying**

There are several narrative inquiry terms that are not used interchangeably in this thesis. In narrative inquiry, participants retell *stories* of their living, which reveal larger narratives (Clandinin, 2016). *Narratives* can be social, cultural, familial, linguistic, institutional, or personal, and are shaped and influenced by stories. Narratives and stories are shaped into a *narrative account*, which is a representation of the unfolding lives of the participant and researcher (Clandinin, 2016). The narrative account is crafted by the researcher and negotiated with the participant (Clandinin, 2016). Finally, while story is not used as a verb in modern language, it is used as a verb in narrative inquiry to refer to how someone is portrayed within narratives. Participants *story* themselves and others in certain ways in their past, present, and future narratives. Similarly, participants are *storied* by others.

**Ethics**

Participants can find telling their story to be emotional, and both Megan and Hailey recounted personal trauma without prompting. The emotional safety of participants is of critical importance, given that relational ethics is at the core of narrative inquiry (Clandinin et al., 2018). While participants can benefit from unburdening themselves of their story, it may also be emotionally distressing (Douglas et al., 2019). Informed consent was received from participants prior to engaging in the study. Prior to each interview, I reminded the participant that they can
take a break or stop the interview at any point for any reason and discontinue their voluntary participation at any time.

Because of the emotional nature of the conversational interviews, during the interviews, I completed regular check-ins with participants. In some of the interviews, it was necessary to conduct a suicide risk assessment following disclosure of self-harm or suicidal thoughts. I recognized the need for this assessment as a professional registered nurse with the skill to do so, even within the researcher-participant inquiry space. Free counselling and crisis resources were available and offered to participants. I also offered the participants an opportunity to debrief after each interview, which would allow them to talk through any feelings the interview may have raised and experience appropriate interview closure (Douglas et al., 2019). Neither participant requested debriefing when offered.

**Participant-Researcher Relationship**

As narrative inquiry is a collaborative and relational methodology, I paid close attention to my ethical responsibilities in the participant-researcher relationship. As someone of similar lived experience and age to the population under study, it is possible I was seen as a peer to participants, affording a place of privilege where I am considered an equal, minimizing potential power differences (Douglas et al., 2019). While this can make developing trust and rapport with participants easier, pre-existing knowledge of this population may result in presumptions (Douglas et al., 2019).

To avoid presumptions in the research process, I prioritized relational ethics within the inquiry. Relational ethics in narrative inquiry attend to openness, attentiveness, presence, contemplation, and response in the relational space, which is a continual process of negotiation and engagement as texts are co-composed (Clandinin & Caine, 2013; Clandinin et al., 2018). Ongoing self-reflection, engaging with my response communities (i.e., my supervisory
committee, and a narrative inquiry reading group) encouraged reflection of how my own personal experiences influenced the research.

To ensure rigor, conversations were had with participants throughout the research process to negotiate meaning and establish accuracy. This allowed final texts to accurately reflect participants’ stories and meanings interpreted from their narratives. In addition, to enhance rigor, feedback and guidance was obtained throughparticipation in a relational response community, a critical aspect of narrative inquiry to share and discuss final research texts with other narrative inquirers (Clandinin & Caine, 2013). Through engaging in discussions with my supervisor, supervisory committee, and colleagues in a narrative inquiry reading group, I received responsive feedback and further examined how my experiences and those of participants have been shaped in relation to my research puzzle. Another important component of development as a narrative inquirer was a University of Alberta two-week intensive graduate course on narrative inquiry (EDES 501), where I discussed field texts, my narrative beginnings, and other reflective writing to better understand the complexities of my narrative beginnings and research puzzle. These relational response communities were intentionally created and encouraged theoretical and methodological development of my narrative inquiry.

Conclusion

Using narrative inquiry, following recruitment, I inquired into the experiences of chronic pain by coming alongside two emerging adult women, Hailey and Megan. We each entered the research relationship in the midst of our own, ongoing personal and professional lives. Over multiple in-depth conversational interviews, a relational space was created, generating data through the emergence of storied experiences. Throughout the research process, I remained attentive to the methodological commitment to experience (Clandinin & Caine, 2013). Situated in the three-dimensional inquiry space, I shaped field texts into interim and final
texts in collaboration with each participant while paying attention to time, place, and sociality. Hailey and Megan’s narrative accounts of living with chronic pain have been re-storied into the two chapters that follow, inquiring into how their experiences of chronic pain shape, and are shaped by, social, cultural, familial, and institutional narratives.
Chapter 4: Hailey’s Narrative Account of Living with Chronic Pain

Preface: The following found poem was created using Hailey’s words and some of my own. Most of the poem consists of rearranged phrases spoken or written by Hailey, excerpted from conversational interview transcripts and artifacts. Phrases that are not direct quotes from transcripts or artifacts are represented in Times New Roman font.

I’m forced to deal with what I feel-
Like a sack of rats,
Wish a garbage truck would run over my back.

Growing up,
I had a lot of friends.
Paris was complete hell.

we did go here and go there, but we've had our house my entire life
My entire childhood, every story of my life fits into that house
Grade nine boyfriend. Trauma there.
from there on everything had pain to it
Quinceanera, canoe trips, summer camp, hospital again.
remembered by pain severity and milestone mental health moments

we wake up, we were born and the pain starts, then we just have to get used to it

Sense of time measured by panic attacks and hospitalizations
Forced to choose between dealing with my trauma, eating disorder, or pain
More diagnoses telling others who I am.

there's no point in telling them about the rest of the pain in my body, because it's always there.
three, four years it took to diagnose my pain.

Metaphors for obscure pains. Lemons, knives, rose thorns.
I thought that that was normal
I’m not a fully functional human
They are more deserving of that chair. they could get farther than I could
I’m broken.
All of me. And the way that the physical and the mental health collides.
why would anybody ever love me, would want this?

why don’t you just let me cut it off for you?
Sickened brain. Cut off the parts that hurt.
I really just want to cut off all the fat.
I’m worried about aging sooner and losing my mobility
that I just won't have as many opportunities as most other people
that I won't be able to achieve my dreams like traveling
I never signed up for this subscription.
because I’m not that strong I cannot be with that person
I might be too weak to even make it through nursing school

Is there really hope for me? Is there?

_Bonding over cuts during fire drill_
A box of letters and we grew closer
Because we were vulnerable like that, whether we like it or not
I love him very much.

Today I went to the gym
I think that it has actually been better this past week
I have more stamina and energy at work.

There is stigma saying it's not a real disorder
paired with the fibromyalgia and trauma it's like, is there hope for me though?
But I have improved a lot. I can tell you that.
little art projects I’ve actually been able to get doing again
I still like to challenge myself
I do see more of my own self worth
I gotta take things one step at a time.

By selecting and rearranging words and phrases from our time together, as well as some of Hailey’s art, this found poem briefly captures snapshots of Hailey’s story and the influence of her experiences over time.

_About Hailey_

I see Hailey as a resilient, creative, and vivacious 18-year-old woman. She has lived with chronic pain since about grade five, suffering from abdominal pain, migraines, irritable bowel syndrome, generalized muscle pain, frequent urinary tract infections, and symptoms of interstitial cystitis.\(^8\) When I met Hailey during the summer of 2021, she was in a transitional state of life.

About a year before we met, she was left suddenly by a serious boyfriend, a relationship that she described as enabling, sheltering, and codependent.

\(^8\) Interstitial cystitis is a chronic bladder condition characterized by bladder pain and pelvic pain. It is often associated with increased urinary urgency and frequency.
Following the break-up, she focused her efforts on her mental health and personal growth. The year also included receiving an official fibromyalgia diagnosis, finishing high school, and getting her second job, where she worked for a year. Two months before we met, she had moved out of the home she grew up in into an apartment with Lucas⁹, a close friend who also has chronic pain. The apartment they shared when I met Hailey was a small studio apartment. Hailey told me that the fridge worked inconsistently, and the kitchen was tiny. However, due its small size, Hailey described that her pain needs could be met easily:

we have everything we need within several meters. And Lucas and I can help each other, take care of each other so like heat. I’m on the loft bed […] so I kind of just ask him to just throw everything up to me instead of me getting down so he- he actually gets me, ah, warms up the bear, gets me drugs, and I do the same for him if it's a really bad day for him so, yeah, it really helps to be here together.

Her loft bed was next to Lucas’s bed in the only room that compromised the apartment, and each time we met she would update me on the status of their avocado pits grown in jars. Recurrent distractions by overweight magpies and large coyotes out their window was a common theme in our conversations via Zoom. She moved after our last official Zoom meeting; I never got to see her new place, but she described it as having much more space and natural light. More importantly, their new apartment is located between her university and the hospital.

In each interaction with Hailey, I always felt she had a sharp intelligence, with an acute self-awareness and exuberant animation – something I noticed from our first meeting. When we met in June 2021 over Zoom for our initial meet and greet, I immediately sensed my own excitement in working with Hailey; her enthusiasm, youthfulness, and creativity felt contagious.

“Every Story of my Life Fits Into That House”

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⁹ Pseudonym used.
Hailey was born in Canada, though her parents are from the Netherlands. With Dutch as her first language, she grew up in Canada, traveling frequently because of her father’s work. Hailey remains attached to her childhood home that served as a home base between time away. Designed by a European architect, Hailey tells me it is an exotic design, spacious with a large ballroom and high ceilings that have, according to her, charming flaws. Her mother is continuously repainting rooms, and Hailey can imagine periods of her life covered by layers of paint.

[…] it's so customized to my family and we have art everywhere and just stories and mirrors from back alleys […] there's like a little cabin in our backyard that my mother built, that when I was younger like my friends and I, we would have sleep overs in there […] we still have the turtle, it's like more than enough, 55 years old, I don't know. So, it's just like every story of my life fits into that house whether it's yeah like, little objects that have little memories associated, associated to them or all the layers of paint that you can't see that are actually on the walls. How many colors are, it's, just like the entire thing is my life.

Picturing her parents selling the home is difficult for her:

we did go here and go there, but we've had our house my entire life for, at least 20 years now […] we're really attached to that house and moving out has been really hard and I’m super stressed with all this moving on kind of stuff […] I’m not ready for that, like it's so terrifying to even think of the concept right now. We have like a massive library and stuff, like my entire childhood is in that house, so this is really, it’s really hard thinking of how they're going to eventually sell it all.

“IT Kind of Just Grew as I Grew”

Hailey doesn’t recall the exact moment her pain started, only that until her late teens, she thought living with constant, debilitating pain was normal. She tells me she has memories unassociated with pain, before grade four or five, “that was so good, like actual good childhood memories I can feel nostalgic about.” As far as the pain goes:

It kind of just grew as I grew, to be honest. […] Starting in grade five, grade six when we went to Paris my depression and my pain was pretty- started being quite prominent […]
I started having more headaches and like up to that point, everything was kind of trace bullets, like oh I feel sick, so I just had too much of this. Or, like, I have a cold, so I have a headache and a sore throat, then it started like making less sense and I’d always be complaining about headaches […] just like pretty basic things that you wouldn't think are abnormal. Also, just like back pain or pain in my legs from this and that, but I was a really active kid too, so I was skiing twice a day every weekend so, and- and I was in swimming and all of that so it was like, you're just sore, right?

Her family spent the last three months of grade five in Paris.

Paris was complete hell. Oh my God, I despise Paris so much. Because we were like bullied and it was just a disgusting place, very dangerous, my mother got cat-called, me and my sister, like 10-year-olds, got like sexually assaulted [inappropriately touched] on the train.

French was not Hailey’s first language, making being liked by peers and teachers difficult. Hailey then transferred to a French immersion program and she tells me she did well at her new school, though her pain worsened further.

my depression started getting really bad and my pain started getting really bad too, so the pain was still kind of, like, I didn't tell my parents about it. Sometimes I’d complain and they'd be like, “take some Advil” and I’d be like okay, sure, doesn't go away, that's just because this is what being human is like.

Perhaps the most current and meaningful relationship to Hailey’s story is Lucas, her now roommate. They met in grade seven on a Thursday, Hailey recalled. Hailey had just self-harmed for the first time and told her parents.

So I was really struggling with that, and this was on a Wednesday, I believe, and then the next day at school there was a fire drill […] so when we do a fire drill we have to sit in alphabetical order so I was in front of him. And I just recognized like, scars/cuts on his wrists that looked a lot like what I was going through, so we started talking like just like, back and forth there on the fields during the fire drill.

Hailey described that at the time, Lucas was going by his previous name and was still seen as a girl. They attended a girls’ night at school together when Lucas was still questioning his gender identity. In grade eight, Hailey paid more attention to the pain, and began noticing unpleasant sensations with touch. Her ability to decipher pain was convoluted by ongoing mental health concerns.
I started paying attention to it and it was like if somebody puts their hand on my arm it hurts, and I was also like, is that pain? Or not? Because I had like this false perception of what pain is apparently […] but I also just ignored it ‘cause I was like I’m just being weird and stuff and I also had like a lot of mental health stuff that wasn’t even being picked up on […]

Still, she had a tight-knit group of friends at her new school, one of which became her boyfriend in grade nine.

I have trauma stemming from that. […] This boyfriend, right. Trauma there, which we believe is a huge cause for a lot of my pain, but there's obviously no test to actually see if that's true. […] From there on everything had pain to it and I actually was able to discern that it is pain and not just discomfort or something.

We never discussed the details of this trauma, but this silenced story became present in the stories she did share with me. Before this relationship ended, Hailey went to France on an exchange for school.

I went to the south of France on an exchange trip for three months from February to April. And there, my mental health worsened too, um the pain wasn't so bad, I was just relying on a lot of painkillers.

There, she experienced her first panic attack; once home from France, her mental and physical health entered a period of significant decline. She recalled to me what happened at a quinceañera that she attended with her friends and boyfriend:

I don't remember any of it apart from like walking in and seeing the people and the dress that I wore and that I still have and then midway through the party, like a quarter way, not long after it started I had a massive panic attack, I even passed out from it, and so I start, I had started to cry so one of the one of the abuelas there, she- she brought me upstairs to the room, so I could have some space and I just started sobbing and eventually I was on the floor just like paralyzed from how bad the panic attack was, um, so that was also like a huge milestone, I remember how painful that was too, like both emotionally and physically.

“All of my Pain was Dismissed by Mental Health and now all of my Mental Health is Dismissed by my Pain”
Hailey measures much of her adolescence by milestone mental health moments and psychiatric hospitalizations. That July, Hailey’s pain further worsened at summer camp, and she experienced what she describes as her most significant panic attack.

So in the girls bathroom I had a huge panic attack again, all- as bad as the one at the quinceañera probably but maybe even worse ‘cause I think it was a longer. I’ve never had a panic attack as badly as that one, that was the hugest panic attack I’ve ever had […] They told my parents about the panic attack. My parents never brought it up, so I don’t know if they were really concerned or anything […]

Hailey’s parents did grow concerned about her physical pain as it continued; however, Hailey was “still […] under the impression that this is just what human, human-hood is like.” Simultaneously, her mental health continued to deteriorate, and she had her first psychiatric hospitalization shortly after, having called the crisis line herself. August 25 to September 25 of grade ten marked:

The most eventful month of my entire life, it was- it was really turbulent and I had been diagnosed with a bunch of different conditions, including major depressive disorder, generalized anxiety disorder, panic disorder, BPD [borderline personality disorder]¹⁰.

Hailey described her pain as being still largely unaddressed. Here, she also started to sense that constant pain was abnormal:

My pain was really bad. I had to stay in the hospital bed very often, and that was not okay with the nurses because we're here to get better and mental health, right, we're all just depressed here! But. They didn't- they didn't have any concern for any kind of physical, physical disabilities, at least back then, it still wasn't really a thing to be having a disability. I still thought I was pretty normal. And so here I started realizing that maybe it’s not normal.

During this hospitalization, the relationship with her boyfriend at the time ended. She continued to attend the same school as him, despite experiencing trauma during this relationship:

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¹⁰ At the time of this hospitalization, Hailey was diagnosed as having cluster-B traits. Hailey was subsequently diagnosed with borderline personality disorder (BPD).
So I had panic attacks every single day and sobbed every single day, and I was stuck in bed a lot of the time, and my parents were like “you need to go to school, this is not good for your mental health, you’re not working with us” and I’m like, “I have a migraine! And my body hurts” and they were like “stop giving us your excuses.” […] So. Pretty much all of my pain was dismissed by mental health and now all of my mental health is dismissed by my pain. Honestly, like there, you cannot have both at the same time.

I knew little about Hailey’s mental health struggles before our first official study interview conversation, yet I was distressed when Hailey did not show for our first conversational interview. I worried that something had happened to her. Had our initial “meet and greet” triggered self-harming behaviors? Was she okay? I worried it was my fault. I thought carefully about my role in this narrative inquiry; I contacted her through the methods we had agreed upon previously and anxiously waited for a response. Later the same day, Lucas informed me she had been hospitalized. Fortunately, Hailey and I met after she was discharged and began our work together. Another time, Hailey did not show for our meeting. Again, I feared the worst, and I worried I was somehow responsible. She had simply forgotten.

Learning how to balance the relational ethics of narrative inquiry with my professional nursing responsibility was difficult. When Hailey divulged details of self-harm or discussed past suicide attempts, my nursing instinct - to do something about it, report it, or make a safety plan - was strong. Recognizing this within myself, each time she revealed thoughts or stories of self-harm with me, I paused. I had to continually ask myself, who am I in this narrative inquiry? I knew that Hailey was accessing regular mental health supports and was familiar with the crisis line. She had demonstrated the ability to seek help when she was a risk to herself, and my role was not to duplicate her health care team. Instead, I assessed for any immediate risk of self-harm, and, not finding any, listened.

She was hospitalized early in the next school year after being found in a blizzard in a state of psychosis and hypothermia. Hailey says that at the hospital:
I wanted to stay in bed a lot, because the pain was so bad and I wasn't getting anything for it and they wouldn't give me the painkillers because they didn't believe that I was actually struggling, like, “it's just because you're not moving enough”.

Following this hospitalization, she grew closer to her now roommate, Lucas. They had drifted apart after grade seven, becoming reacquainted at camp the summer after grade nine. Lucas gave Hailey a box of letters wishing her well when she was hospitalized, and he became a primary support for her from then on.

[...] he really supported me after that [...] and we were just like there for each other again and from that point on, we were just a lot closer and became much better friends and also, just like, Lucas, it's really a coincidence that Lucas has the same physical, well, similar physical disorders, and issues and mental health issues but also because of that we’re like always on the same page with that kind of stuff [...] 

After discharge, Hailey attended a three-month outpatient mental health program which improved her relationship with her parents, and she started discussing her pain more with them.

I was opening up about it more and I discovered that's not what normal humans have, experience, they aren't in pain since they were born. So my fibromyalgia was in question, but we didn't want to say fibromyalgia so I started, I was, I had a lot of connections to different resources at this point, including psychiatrists and physio, so all the testing started there, grade 10.

After the outpatient program, Hailey returned to school, but at a different school which had a mental health program, including a designated classroom Hailey could retreat to during periods of increased pain, or, when experiencing panic attacks.

I couldn't attend most classes, because I’d have so many panic attacks and a lot of the time, I would just have to sit in their mental health classroom with like three heat packs or ice packs um and still there were no answers right. [...] I wouldn't have survived high school if not for that program so I’m very grateful for that one as well.

“I was Just Really in Denial”

Fibromyalgia was a possible diagnosis when investigations for the pain began in grade 10, a condition which Hailey initially learned about from Lucas:

He tells me he has fibromyalgia so I start looking into this because I love him very much, I want to know what he's dealing with, so I start reading on fibromyalgia and I’m like, oh,
is that me? I don't think that's me. And I was just really in denial starting there like, thinking it was fibromyalgia so.

Her doctor started testing for other potential causes of pain, since fibromyalgia is diagnosed by exclusion. During this period of uncertainty, Hailey began her own research, and would often ask her biology teacher about various ailments, including leukemia.

I was just also doing a lot of research on myself um at one point there was a possibility that I had leukemia like looking at my symptoms and the health system’s really slow, right, so I’m here in grade 11, in bio 30, just trying to do my best in this class, right, and then every now and then like at the end of class I would slowly like, come up to my bio teacher and be like, do you know how leukemia works? He’d be like, “[Hailey], are you okay?”

Early in grade ten, Hailey was diagnosed with anorexia nervosa binge purge subtype. Her mental health remained poor, and she was hospitalized for two weeks at the end of grade 10. One positive memory Hailey recounted to me from her high school years was a canoe trip at the camp she attended each summer:

I don't remember whether it was actually two years ago, or one year ago now, but we went on the Athabasca river, I was with a group of nine other people. Didn't know each other, got really close over this trip right. It's kind of like the point, so we were canoeing for 18 days […] it was a long, it was a lot of canoeing and so that was a huge challenge for me and it's still like one of the most amazing and important experiences of my entire life.

Pushing herself was not without consequences. She had begun investigations for her pain with her family doctor, and had started new medications for mental health and pain, which helped, however Hailey remembers feeling like a liability to her peers. Fortunately, the group was understanding, which was an important first experience for Hailey.

Sometimes I would just be throwing up out of nowhere, or, because of pain usually or just like my body hurts too much today […] I was never guilt tripped by it or challenged if it was actually real or if it was just excuses, it was like that had never happened before so that trip was pretty monumental.

At school, it was difficult for Hailey to fit in and make friends. Her mental and physical health challenges made it difficult for peers to approach or accept her.
Especially in high school, people were just so unsure of me and kind of intimidated by the fact that there were clearly things going on with me and I had panic attacks here and there, and I had to take the elevator sometimes, things like that [...] like people did notice those things, and it kind of makes me stigmatized, you know?

Attending school became difficult because of the pain, and Hailey was hospitalized once more following an overdose before finishing high school. Hailey never shared details leading up to, or of, the overdose:

It's kind of foggy but that wasn't much of an important stay, and then I, as you know, I graduated high school in January, having to do that extra semester, because I couldn't, wasn't able to do real school at the time you're supposed to do it so.

“It's not Good News to be Diagnosed With Fibromyalgia, but it is Good News to be Diagnosed”

After over two years of investigations, in the summer of 2020, Hailey was diagnosed with fibromyalgia.

And at this point my doctor says, actually, I think it is possible that you have fibromyalgia. I’m like, wow, knew that for two years now. So it wasn't really, it was, it was pretty easy for me to accept it at that point.

Hailey understands there are positive aspects to having a diagnosis, such as validation and improved self-management, as well as more effective and appropriate medical care.

It's not good news to be diagnosed with fibromyalgia, but it is good news to be diagnosed, because then you know where to go from there. It's like kind of the same with being disabled, like, it's not good to be disabled but it's good to be able to tell somebody one thing [...] it's also really nice to have a word that describes all of it. All of the specifics, not just a vague idea of something and then be able to go into treatment from there on.

Yet, finding answers to her questions after diagnosis remained challenging:

My doctor wasn't a great source of information. I had questions for her about fibromyalgia that she couldn't answer and I had a lot of questions about how pain can be started, like triggered by trauma and these things, these things were definitely hard to find answers on [...] Lucas knew a lot more about it ‘cause he’s had his diagnosis for a lot longer than I have. [It] was really hard to find great sources of information in general.
When Hailey was diagnosed with fibromyalgia, Lucas made her a card congratulating her on her diagnosis. She asserts that being able to talk to Lucas, who also has fibromyalgia, was fundamental in establishing the knowledge and supports to independently manage her fibromyalgia. Because of her fibromyalgia, Hailey identifies as having a physical disability.

I would definitely call it a disability, because I need so many accommodations that I need my doctor to write a note saying “yes, this is valid, she actually has these disorders, you need to allow for these things” […]

Hailey described experiences of discrimination as a result of her disability, and reflects on how she has learned to hide her diagnoses:

I was pretty much an open book in junior high. Even though it scared some people […] I never really hid it until recently […] I’ve had to be really careful, just like the things I wasn’t careful with- with my disabilities when it comes to working […] So, I’ve had to get like a doctor's note and stuff and I don't really tell other people about it at all, unless I actually know them quite a lot.

When she discloses her fibromyalgia to someone new, she keeps it short, telling them she has a chronic pain disorder. “Unless they ask for more, but usually they're like, ‘Okay cool’ without really caring,” says Hailey. When talking to friends or family, her approach differs.

[…] if I’m catching up with someone, like I’ll give them a bit of a rundown. So it's mostly just like, I also group it into a general pain that's everywhere and then what feels like mostly muscular pain, specifically in these areas, and then migraines and then um digestive tract issues, or mostly just like chronic constipation and then UTIs like normally I scrunch it into that.

**Dismissal: Family, Health Care, and Multiple Diagnoses**

Dismissal of her pain started early on, and Hailey absorbed this into normalizing pain as part of the human experience, perhaps masked by symptoms of depression. As Hailey advanced in her teen years, she began to realize that persistent pain was not normal, and her eating disorder, sexuality, gender, and trauma contributed to her experiences of dismissal.

“It Took Them a While to Finally Believe me”
I wonder to what extent Hailey’s parents’ dismissal of her pain contributed to her belief that persistent pain was normal. Hailey recounts to me her thoughts as a child:

I just remember having a lot of pain back in grade five-ish but I kind of stopped mentioning it, because my parents were like, “yeah, we know you are. We just walked a while, suck it up.” [...] I started not telling them about it, because every time I felt kind of dismissed and I was like “oh, so this is just what everybody feels like, that makes sense.” [...] I think that majorly helped me develop that thought about how humans are just always in pain and it's just like- like why, why did God do that to us, why did evolution do that to us, huh? And so I never really questioned that for a really long time. So I thought I was normal until I actually started talking about it to my friends, because my parents were just like “just suck it up.”

Hailey remembers a specific time in grade six when she felt taken seriously by her parents.

one of my friends was talking to me and I just saw like in my vision, it was just like squiggly, like squiggly near her forehead, and it wasn't associated with a headache I was just like, that's kind of funky. So I remember that very specifically because it was like the first time I had something like that and I brought it up to my parents, my mother was like “that could be something to do with your brain” and so that was the first time also that my parents were like, “that's weird”. But we didn't look into it because it didn’t happen again.

Grade eight was when Hailey began paying more attention to the pain and telling her parents. Establishing credibility of her pain took time, and it was initially dismissed by her eating disorder.

It felt like they thought I was just like sore and stuff and complaining about that [...] eventually, I started passing out more often and they were pretty angry about that ‘cause they thought it was the eating disorder and honestly it probably was but the eating disorder was kind of also based on the pain [...] it took them a while to finally believe me [...] finally like I’m collapsed on the floor at school and I need them to pick me up – “oh, okay so maybe it is that bad”, you know. Even though I’ve always, I’ve already been telling them that it’s getting to that point.

Around this time was when physical touch became painful, affecting her relationships with her parents.

I wasn't okay with my parents touching me anymore, I wasn't okay with hugs, and this was really, really bad for like, angering for them [...] they would get angry at me because I wouldn't let them touch me [...] that was like a really big shock to my family, even when my sister was moving out like three years ago um like she wanted to hug me and I
didn't want to hug her and I was not okay with hugging her and my mother still guilt trips me about that.

Because of her suicidal ideations, she stopped downhill skiing. She was at an advanced level, and she and her parents were concerned about the risk of committing suicide while skiing. Hailey still feels that her father is disappointed in her for having to quit skiing.

like my sister and I were pretty much born to be his ski and diving buddies. He makes that joke a lot. I still feel like a huge disappointment for suddenly stopping that.

When fibromyalgia was being considered as a diagnosis, Hailey’s mother “was not on board with that she- she wanted to do everything in her power to figure out if it's something other than fibromyalgia, so she was in a lot more denial that I was because at one point I had just completely accepted it,” Hailey told me, and she believes her family’s denial of her fibromyalgia diagnosis came from a place of love.

it was a lot harder for my mother and my family to accept that, which I believe also is out of love right, because if it's something else, then that might actually have a solution to it. But it’s fibromyalgia, so it's like the gray area.

Though her parents may have dismissed her pain much of the time, Hailey now appreciates their “tough love” approach, for it encouraged her independence.

I still like to challenge myself, and if they were not like that, like it was just things like “I’m not going to carry your skis for you, you’re five years old, you can do it”. Just stuff like that it just, it was definitely part of being independent more than it was about dismissing me.

Hailey recognizes her self-management, communication, and self-advocacy skills developed early on because she was both expected - and allowed - to make her own decisions at home and at school.

My parents always like really relied on me to figure out that stuff mostly for myself […] I ended up being very good at communicating when I needed to go to the hospital and stuff […] I talked to my teachers about it and, basically, I was completely in control of my schedule like no other student ever could have been. They were fine with me not going to class, coming to class when I wanted to, leaving class at any point, and my grades were
still very, very high so apparently from that point it definitely felt like all the adults trusted me, even though I was only 16 and 17.

In grade seven, Hailey told her mother she was bisexual; her mother did not seem to fully believe her at first. Hailey started calling herself pansexual instead, and it was after dating a girl that her mother accepted Hailey’s sexual identity. Social repercussions that Hailey experiences because of her sexual identity are not unique to her family. Imagining what her life would be like if she was heterosexual and did not have mental health concerns, Hailey reflected to me,

There’s that haze of, are they queer? Or why are they always complaining about this and like, if I were just straight and neurotypical like that haze wouldn't be there and I think just people would be a lot more accepting. And probably like less intimidated too. And they would listen to me more about the things that I’m saying ‘cause it's not as much to take in […] people would take me seriously quicker, you know?

“The Pain Stuff is Already Dismissed, by Like Everything”

Of her multiple diagnoses, Hailey feels most dismissed for her eating disorder, because “the pain stuff is already dismissed, by like everything.” Both Hailey and Lucas adapt their narratives when accessing health care, having learned from their experiences what to omit to have only their presenting complaint assessed in the emergency department.

he also has trauma […] that always like adds another layer. But we both have learned to like not mention these things when we're in the ER because, otherwise, though, they like take that into consideration when they shouldn't.

I wonder what silent stories have shaped Hailey’s understanding that past sexual trauma should not be considered when attending the emergency department for certain issues.

Until she turned 18, Hailey felt she had little autonomy in her care. Her parents, in conjunction with her health care team, would decide whether to address her trauma or her eating disorder - although both are connected - along with her pain. “They’re together, it’s out of one

11 Hailey uses the term neurodiverse to refer to her mental health diagnoses and autism spectrum disorder diagnosis. Neurotypical would refer to someone without any of these diagnoses.
body,” Hailey says, “[…] I never had the choice that I could make myself, I had no influence over which ones to do first.” During the diagnostic investigations, Hailey discovered the stigma that accompanies a fibromyalgia diagnosis.

I was told by the people that were doing tests on me that fibromyalgia is like the gray area that you, nobody knows anything about and it's what you'd be diagnosed with if we, if you can't figure it out, like it was- it was definitely still kind of that but then by […] last summer like it was still kind of that stigma saying like it's not a real disorder.

Hailey feels her pain is dismissed because she has an eating disorder, and vice versa.

[…] It's just a vicious cycle […] I’ve been dismissed with that very often saying “oh, so you're struggling with this? Okay, well, that's because you have an eating disorder probably. Come back to us when you don't have an eating disorder. And then we'll do tests […] if it's an eating disorder I’ll get dismissed for another reason they're like “Oh, you have pain? How about you recover from the eating disorder? Oh, you have an eating disorder? How about you just find a way to deal fibro?”

Hailey says it is harder for her to talk to health care providers about chronic pain than it is with friends, and this includes her family doctor.

I don't feel comfortable with her anymore because she's pretty dismissive now, and she only wants to focus on the problems that we've been targeting and just a lot of the time I’m scared actually of telling her about another issue, because of the way she'll react and I don't so, so, I don't […] she'd be, like, well I can't help you with that it's like, I know, so I just won't tell you. Like we already have so many issues in the first place that doctors get impatient, and they get kind of annoyed […] normal people like healthy people, they would bring up those like smaller issues to their doctor, whereas I wouldn't and I think that's kind of telling […]

Referring to her pain as “just the fibromyalgia”, the chronicity of her pain seems to equate irrelevance to Hailey. She says, “it's like a waste of time for other people too, like there's no point in telling them about the rest of the pain in my body, because it's always there.”

“It’s Like a Checklist, Like, ‘Are we Going to Take you Seriously?’”

Hailey is quick to tell me how she feels taken less seriously as a female for two reasons: having “more complicated hormones” and menstruation.

[…] as I’m already a woman there's already like a foundation of discrimination, like, not taking me seriously and it's always there. Always like, “oh you're female, your hormones
are more complicated” like I’ve actually had a doctor say that to me […] I once mentioned it to a doctor saying I feel like […] doctors don't take me seriously as much as they do men, and then they said, well, you do have more complicated hormones […] it's like pretty invalidating […] it's also like whenever, I like, they say, “when was your last period?”, and if I say I’m on it right now they're like “oh okay”, as if, like that means that, whatever the issue is it's like partly because I’m on my period as if, like, I’m overreacting.

Hailey notes that, “if I’m in the ER and realize that I’m, I’ve been assigned a male doctor like. It's just like please, please listen to me […].” Early in her mental health journey, Hailey and her parents were seeking a regular psychiatrist for her, and she remembers feeling dismissed by two male psychiatrists. She describes this as the first time she felt treated differently as a patient because she is female.

like the first one […] I felt completely dismissed. My mother was there during this appointment and she too was like pretty, pretty pissed at this guy for completely dismissing me. And I don't know if it, if that's also because I’m female but that's definitely the first time that I felt more dismissed by a male doctor and then the next one, too. Like also male, white guy, pretty old. Very uncomfortable, very uncomfortable to be in the presence of because it's like I was young, too, but it felt like he was talking down to me. I’ve had that a lot and it feels like you're talking down to me. If- I don't know if it's about my age, I mean I’m still 18 and I still feel like I’m being talked down to but yeah that really sucks […]

Her earliest experiences with physicians seem to have shaped Hailey’s narrative that male physicians are dismissive, particularly Caucasian male physicians.

[…] now I’m kind of realizing how there's a bit of a pattern with white male doctors. That are a little bit shittier and that like, it's not surprising to me because, especially white male, males, like, they already have that white privilege and all that shit.

She has had more positive experiences with health care providers that are female and closer to her age.

if whenever like, the person that I’m talking to, like the health care professional I’m talking to is younger, especially like in their 20s, early 30s, around there, like then it feels a lot less stressful I guess because they, especially if they're female, to be honest it's like, they've already- they've gone through that too, you know?
She remembers telling an older nurse that her pain was severe while asking for a heat pack. According to Hailey, the nurse’s response was, “Honey you're not even, just wait until you become my age like. Everything hurts here. You don't even- you shouldn't even complain.” It seems her pain is perceived as less valid because she is young, and perhaps because her pain is not visible. Perhaps the nurse was not knowledgeable about caring for someone with chronic pain and multiple diagnoses.

It's like also on the bus right if, like, if my pain is really bad I’d rather just sit in the front like where those- like on the priority seating for handicapped people or like pregnant women because I don't have to like maneuver through the seats and over people and then like if older people do come on everybody expects me to stand up, even though I might be at the same level of pain as them because it's just invisible and I’m young so it's just like it's always kind of this…like it always feels like people think you're so young, that this, like people have it way worse than you do.

Invalidation due to age seems a common response to Hailey’s pain in social interactions.

A lot of the time they're like, “You're only 18 years old, just wait until you get older.” And it's like, well that one, that's not very helpful, thank you for that, though; two, you're just completely dismissing what I’m saying here […]

Hailey feels her sexuality adds to not being taken seriously when accessing health care. She explains, “it’s like a checklist, like, ‘Are we going to take you seriously? One, she's female; two, she's queer; three, she's on her period; four, she has other diagnoses.’” She feels there is an automatic assumption that because she is queer, she is less emotionally stable. She also tells me that since care providers assume she has already experienced trauma or discrimination because she is queer, subsequent adversity is perceived as less significant.

Like it feels like they use that as a reason as well, just to put on top of everything else saying, “okay so you're already at this point because of all this, so this isn't even that bad for you”, you know.

These interactions have likely shaped her perception of the patient-provider relationship.

Doctors always start at zero percent trust, instead of 100%, it goes […] up instead of down […] they begin without any trust in you and expect you to build their trust, instead of starting from the top.
Work: “He Pretended to Care and Then Completely Dismissed it”

Hailey was still working at her first serious job when we met. She enjoyed working at the arts and crafts store, a job she got after graduating high school in January. Initially, her managers were understanding about her health and pain needs. These managers had lived experience of chronic illness such as chronic migraines, irritable bowel syndrome, or mental health issues. She told me she had been dreading telling them about the accommodations she needed, but her manager “was really understanding about it and like really appreciated me telling her about it and actually asked me some questions too, to like understand it”. Unfortunately, the management changed and her experience at work became a significant source of stress in her life because of the new manager.

I was really scared to tell him about my chronic pain, because he was like, I just didn't feel safe around him [...] he was like I didn't know about your disability I would love it if you told me about it, and so I started- started like explaining what I have and then he said, “that doesn't matter” [...] every time I tried to bring it up with him, he pretended to care and then completely dismissed it [...] I collapse at five hours of my shift, like I actually do and [manager’s name] doesn't even care and so I’ve had to like talk to my doctors to give me a doctor’s note which also costs me money [...] he pretends to like understand and then later as soon as he sees symptoms of me he gets mad at me and starts gaslighting me.

To Hailey, hiding aspects of her identity becomes important to avoid being seen as unstable.

When talking about her workplace, she said:

Yeah it's always like something that you need to omit because otherwise. Like. The foundation on which they're looking at you, is like unstable if they already know that you have these other problems. Like chronic pain, being female even, being queer, trans, having. Like having. An autoimmune disorder, you know [...] When Hailey calls off a shift – for example, when her knee was injured recently – weeks of her shifts are cancelled, affecting her ability to earn an income.

Like that also just adds to. Like the anxiety of getting hired or not, if they know about your disability, but also if they do find out about your disability and you can't get any accommodations they'll fire you. But not actually fire you, they'll just not give you shifts
[...] if I were treated like a normal person and I’d have these off days like it would still be really hard to make a living, but I would think I would still be able to do it, but with this and being treated the way that I am, no [...] I couldn’t afford my meds today.

Comparing herself to her peers, Hailey is forced to rethink her future.

I have like friends that worked full time like [Austin12] he worked at Co-op. Eight-hour shifts, but at cash. Like I would never be able to do that [...] I need to consider what my work should be differently, because, like. I’m like having to think about like just rethinking nursing school, for example, like am I able to do that? And that completely changes, like my plans in life, and what I want.

Making the Invisible Pain Visible: “That's Kind of What art Does”

As our time together evolved, I began to see the importance of Hailey’s art in portraying and expressing her otherwise invisible pain. In grade ten, she kept a visual pain journal for three to four weeks. This helped her understand what she was experiencing and to keep track over time; it was also used for Hailey to communicate with her doctor.

I was still in high school and started getting more into the pain with my doctor because I had discovered like “Oh, this is actually not that great and it's actually pretty serious”, so I started doing this to show to my doctor. But, to be honest, I don’t remember ever showing it to her.

While the pain journal may have helped Hailey’s parents understand, it made her pain worse.

it actually seemed to make the pain worse because I was focusing on it so much. So I stopped pretty quickly [...] it was kind of almost validating to myself, I guess, because I kept trying to ignore it [...] I actually was so much more conscious of the pain and it was supposed to be making it better, but it made it so much worse. And I was, like my parents finally started kind of understanding a bit more and there were days where I didn’t go to school, and there were days where I could only sit on a chair.

Hailey and I reviewed a few pain journal entries together. She effortlessly listed the different sensations recorded in her pain journal from three years ago – pain she still experiences. She explains to me some of the recordings in her journal:

12 Pseudonym used.
Joint pain [...] femur [...] that one still happens [...] I just have to like kick my leg around and it's like it falls back into place [...]. The jaw pain is still really bad [...] still have no idea what's going on there [...] general neck pain that's still always a thing, same with like the bone muscle, maybe nerves [...] very brief short stab to my abdomen which is triggered by, it's related to my trauma actually, like this one I’ve completely figured out and it only happens when I think about one very specific thing that has to do with sex [...] all of these, is just like the general pain like, that, has always been there and there's no progress made on that, [...] my abdomen hurts a lot [...] at least three times a day [...] And then the back shoulder pain plus lower back [...] my trapezius, that's pretty fucked up [...] Yeah the- my right/left femurs and pretty much all of these [...] sharp pain inside ears sometimes happens too [...] I even had a burst ear drum at one point, so I have a lot of pain [...] 

One entry stands out to me (Figure 1). Dated December 12, it has more black ink than the others,

and the word ‘intense’ is legible. She explained:

I was just like walking up the stairs it was very brief but extreme like, it was like somebody just stabbed me, um, I remember collapsing. My mother pretty much witnessed it. I do still sometimes get things like that where’s it suddenly just a really intense pain out of nowhere and like I, like I’ll often fall down or like- hit, walk into a wall or something or like almost fall I guess.
When I had just begun meeting with Hailey, I came across a poem on Instagram that read:

our scars
are evidence that we
existed.

but most importantly
that we survived
-@fguerrapoetry

Figure 1: Pain Journal Entry for December 12, 2019

13 All images contain original content and are provided with permission by the participant.
I initially thought about my own surgical scars when reading this poem, but then I reflected on Hailey’s self-inflicted scars. An entry in my field journal reads:

I am almost finished Hailey’s chapter, the very first rough draft that is. I was taking a short movement break near my desk that I have moved downstairs, looking at the photographs on the wall that once hung in my grandparents’ condo in Canmore, a condo that defined so much of my childhood and early adulthood by memories. I thought about Hailey’s self-harming, and the quote I pasted here earlier about scars. Scars are visible, but pain is not. Without scars, what do [we] have to show for [our] pain? Scars are marks of survival, of healing, of recovery. Scars are seen as honorable. I am proud of my scars, for they are proof of resilience. With nothing to mark the pain, though, what do we have to mark us? (Field note, October 04, 2021)

Our pain is invisible; chronic pain is an invisible illness. @fgeuerrapoetry’s words imply scars show something in the past tense rather than the present and future – survived rather than surviving. For Hailey, there is no visible proof on her body of being disabled, but she has found ways to make her pain more visible both to others and herself. The need for recognition of her pain is important, and she explained to me in an email how she used to make visible the impact of living with pain:

in the past I’ve used makeup to create fake bruises or to darken my already-prominent eye bags and lighten my already-pale face. I used to do this in high school sometimes. When pain is bad all the time, people don’t seem to take it seriously when it’s EXTRA bad, y’know? Not until they see some kind of proof. There have been times where I really felt that desperate to be seen and to get validation.

Creating art is another method that Hailey uses to express living with a pain disorder.

It's really nice to be able to see a visual because that's like the worst part with invisible illness, like even if your body's hurting so much. Like yesterday, for example, my body was hurt- I was really struggling with my pain and I said to Lucas I wish that where it hurts most, it bruised. Like that there was a lot of bruising so that you could at least look at it and see that there's something there, and like that's kind of what art does, it's like an actual visualization of what's going on.
Hailey shared with me the piece, “Maggots” (Figure 2), which represents her abdominal pain; “Maggots” was a code word for Hailey with her second boyfriend, Caleb14, when she was experiencing this pain.

Figure 2: Hailey’s Art, "Maggots"

Our second meeting, she told me she had felt inspired to create a new art piece after our last conversation (Figure 3). I recall feeling immense honor knowing that our conversation had inspired this, and she wished to share it with me. Using flower petals and acrylic paint, the art she created was powerful to me. I mistakenly thought the flower petals were wings, and Hailey quickly corrected me. I asked her what the painting represents to her: “it’s the pain, in my

14 Pseudonym used.
back. Like it's not much deeper than pain and eating disorder thoughts and suicidal thoughts.” Later, Hailey elaborated on this piece via email:

As for its representation of pain, I felt that this is just a comforting visual to have of it. The way it's rough, almost cloudy yet sharp around the edges, stemming from what almost looks like a decaying or fragile skeleton; as if the pain represented by the flower petals is inside the bones and happens to be leaking out. Or, at least, this may be what it would look like if it were leaking out.

**Figure 3: Hailey's Art**

**Romantic Relationships: “Some of my Absolute Worst Moments”**

A good portion of our conversations were centered around the romantic relationships in Hailey’s life. When Hailey met Austin\(^15\), “I gave him like a little note that said all of the physical and mental issues that I have and said, are you well, are you ready to, like are you sure about this?” She described the relationship as toxic and felt he did not respect her or her pain.

He just wanted sex all the time. And I just did not want that, because I was in pain and he didn’t really respect that. [...] he treated me like I was apologizing for not going to visit

\(^{15}\) Pseudonym used.
him and to fuck him because I was saying sorry, my pain’s bad […] Instead of like, “I’m sorry to hear that. Let me know if there's anything I could do” it was always like him treating it like an apology, as if I owe him something.

Partway through our time together, she ended her relationship with Austin, and the breakup had an immediate positive effect on Hailey.

it's been so much better and not being tied down by him and just constantly feeling like I owe my time to somebody else and it's been a lot better and to be honest that's been kind of empowering too. I might even consider going to Europe in August, by myself.

Feeling empowered, Hailey got back in touch with an old friend, started spending more time alone and with friends, and began going to the gym again with her mother. She also noticed less pain.

I felt like I had more stamina. So damn, maybe that’s how the human body might work so that was also pretty, pretty great, like I’ve had a lot more stamina and less pain at work.

Hailey has had three serious boyfriends, each relationship a narrative of turbulence and chaos. She never referred to her first boyfriend by her name, nor she did disclose her pain to him.

Compared to her most recent boyfriend, Austin, her second boyfriend, Caleb, was:

a lot more complicated um. It was just. It was wild, that relationship, like I definitely had some of my worst moments in that relationship regarding the pain aspect […] whenever my pain was bad he would coddle me and to be honest, it was nice, it was nice that he was carrying all my things for me and like treating me so nicely as if I was kind of fragile, but at the same time, like that was not something good in the long term.

Her relationship with Caleb started before the COVID-19 pandemic, which acted as a catalyst for deteriorating her physical and mental health during this relationship. When the first lockdown happened, Hailey stayed with Caleb on weekends.

I associated that with more pain, too, because we were spending all that time in bed, and sometimes like he would, he would get, you know, Warm Beary [bear-shaped heat pack] for me and like make us tea and get us yummy food and I just remember constantly being in pain and it was definitely because we were just staying there […]

In this relationship, they focused on the pain more, and Caleb’s willingness to support her extended too far for Hailey.
it was completely enabling and he sheltered me. And didn't really let me do things for myself like he's, he's all he was also a cute, a lot of like a gentleman, and he would do everything for me and I was just like. It was completely codependent.

Some of Hailey’s memories of her childhood home are also tied to this relationship and her pain:

I had some of my absolute worst moments there and I couldn't go to school for like five days, I was completely bedbound. And I couldn't even go up the stairs so I was like stuck in the living room and just like my entire life, if one of us was sick and we couldn't go to school, we would stay in the living room. And people would like do things for us, and I was just stuck on the couch for days and the pain was so bad that [Caleb] had to be there to help me up the stairs.

"It was the Most Painful sex Ever"

Because Hailey experiences pain with physical touch, navigating the beginning of a new relationship can be difficult.

It actually took like quite a while for my body to kind of get used to [Austin] 'cause it was hurting […] it took quite a while for my body to trust him 'cause everything, like whenever somebody touched me it hurts, and so it took like about a month […] maybe a month into our friendship/relationship where we kissed for the first time, so by then everything had like my body had calmed down around him. Yeah but other people: no, thank you.

Hailey’s first experience with sex was non-consensual, before she met Caleb or Austin. She believes this influenced the progression of her chronic pain, and she struggles with trauma in subsequent relationships, experiencing panic attacks, flashbacks, and reactions to sex like vomiting. Towards the end of her relationships with Caleb and Austin, she was able to make progress. However:

it's still not easy but it's just especially the trauma’s bad, I mean the panic attacks were bad because it would feel like it's happening again. So it would be like really sharp abdominal pain and even if he was just like touching me, I would, it would be like suddenly he's grabbing me, even though it's not what was actually happening.

While never officially diagnosed, Hailey thinks that she had vaginismus, making penetrative sex painful, especially the first time with Caleb.
it was the most painful sex ever and it was also like my first time having consensual like penetrative sex. And it was like one of the most painful things I had ever felt and I’m pretty sure that that was largely just because of vaginismus […] But since it was like my first time actually getting into it consensually, I thought that that was normal and I thought it was normal to bleed from the first time that you have sex too and it apparently wasn’t.

Living with chronic pain, and not knowing any differently, I wonder how her experience might have been different if she had received information before first sexual penetration on what to expect, especially on sexual trauma and how it can affect sexual functioning. Would she have stopped with Caleb when it hurt? How might her relationship with her body be different? Though she noticed improvement with the vaginismus, Hailey continued to have sex despite pain. Hailey’s body became a battleground of sorts, or perhaps an alarm signal for underlying emotional distress.

I started getting a lot better with Caleb and also towards the end of Austin like I said but yeah it, it would often be really bad. Like abdominal pain and honestly, I wonder if all, if some of the UTIs I’ve had weren’t actually UTIs and it was just my body being angry about having sex […] So, I don't know, I think it's possible that it's also just my body's response to sex and knowing that, like deep down, I’m kind of not a fan of what Austin was doing.

Hailey’s chronic pain and sexual trauma also make her more vulnerable in sexual relationships. The pain itself, in addition to post-traumatic stress, makes trust in her relationships crucial. One way Hailey puts trust in place with sex is to engage in bondage, discipline, dominance, and submission (BDSM). It becomes a way to retell and relive her past trauma to create her own narrative, thus regaining control. She explains, “for like CNC, consensual non-consenting, like it is kind of like therapeutic like going through it again and being able to associate it with something that isn't sheer terror.”

For Hailey to enjoy consensual non-consenting or BDSM, though, trusting her partner is even more important. Without that, she finds it hard to discern between “good pain” and “bad
pain”. Austin’s lack of respect for Hailey’s pain outside of their sex life began to affect her experience of BDSM:

eventually like I couldn't tell whether that was actually just a sexual thing or something that was actually happening, and I think that also decreased my libido ‘cause it started hurting more as soon as I didn't trust him as much [...] discerning between those two [good pain and bad pain] is always hard and it's just like I think that, especially was making it harder and harder to do like kinky stuff with Austin [...] The day before Hailey moved into her new place, she sent me a piece of slam poetry she had written. I can see how her trauma was perpetuated in subsequent relationships and continues to cause physical pain in simple daily functions. Her poem reads:

My very first lover
-of those who meant it-
the first time I noticed,
I'll never forget it.

he smelled of roses,
and gave me one too,
but he plucked it himself
and little I knew
of a gardening hobby he'd
yet to pursue. (he was a virgin)

He gave it to me
unshaven of thorns
and I thought it was good (ridiculing tone)
for I wasn't warned

But three years passed
and now I still buckle
in pain
from the game
I shouldn't have played
the rose he had laid
inside my pathways
had rotted and wilted
and in me there's stayed
the thorns of the rose [heavy on tone]
in my tract did invade
so well displayed
by the state of pain
so awfully great
every
single
time that
I...
urinate.

Hailey wrote this poem for a poetry book she has been working on entitled “Poems of Obscure Pains”. She told me this poem was about:

Pains based on my awful (but not uncommon) morning that I had to cancel plans for due to the usual flare-up of UTI pain mixed with constipation pain and back pain. [...] The poem starts with the first time I had consensual sex with [Caleb] - the two-year-long relationship - and how it felt like something went terribly wrong during the penetration. I wonder here and there if that experience may be linked to the recurrent UTI-related pain, as well as other sexual trauma. The way our relationship withered towards the end, the trauma, the painful sensation that keeps coming back, and how I’m full of regret is represented via the conceit of a thorny rose. The issue is that it ended kind of humorously so I don't know what to do haha. It's kind of more for slam poetry, so to be spoken instead with specific intonations, so that's what the words in bold mean.

In her email, she attached “scribbly doodles” (Figure 4 to 6). Figure 4 represents the sensation of a thorny rose in the urethra, Figure 5 represents knives dripping with blood, and the image on the far right of Figure 6 is about another specific pain. Figure 6 was a digital sketch she created to clarify my misunderstanding of initial scribbles; I thought Figure 5 was of a male body, however Hailey corrected me and highlighted the issue of using pen for sketching. In her email to me with these drawings, Hailey wrote:

Currently it’s quite general; there are so many abdominal pains that feel like knives stabbed into your flesh. But when drawing this one I had in mind a specific, brief, intense pang that I get whenever I have particular sexual thoughts. I’m going to name this upcoming poem Corinthians. While I’m not religious, I know a lot about the bible (I had a year-long traumatic religious phase 😞) and Corinthians is the first book that paraphrases God’s telling humans that sex before marriage is a sin. The gist I’m getting at is that this pang I get feels like a punishment for enjoying sex after what I’ve been through.
Looking forward, Hailey has learned what she needs to enjoy sex in the context of her pain:

I don't really want to date anyone for quite a while, but I think [...] if I am going to have a sexual relationship with someone I need them to let me explain in detail, like what my pain is like and I need to be able to trust them that they understand which [Austin] never did [...] it's really just trust like it always is, it’s just with pain in the mix I guess.
“Why Would Anybody Ever Love Me, Would Want This?”

Much of Hailey’s storied life shared with me was eerily similar to mine. At times, I felt like I was time traveling to visit a younger version of myself. An entry from my field journal reads,

So often, I relate entirely to [Hailey’s] experiences. I am a woman with chronic pain too. I was once a young woman who experienced such strong anger, I did not know what to do with it either, just like her. I, too, have experiences of trauma and anorexia in teenagehood that I believe contributed to my pain. I had perfect grades like her, and hid my pain unintentionally because I didn’t realize that I was sick. I, too, experience disbelief and dismissal from care providers and strangers. I, too, went through the powerfully emotional stage of growing into yourself as a young woman while simultaneously coping with a fluctuating and life-changing medical condition. (Field note, June 28, 2021)

Hailey’s story, like mine, is turbulent. I find Hailey’s insight into the vicissitudes of life remarkable, and she tells me she wouldn’t have the same friends if not for her diagnosis. I doubt her self-awareness, maturity, and ability to advocate for herself would have been as developed either, without her diagnoses, and these are all attributes that assist Hailey in managing her pain. She told me:

I was always like pretty mature quite soon like, like, for example, when I was in high school like after the first year. I completely started advocating for myself and my teachers.

I once asked her how she understands the cause of her pain. “Pretty sure it’s just my brain fucking me over,” she responded. I wonder if this self-blame associated with her pain contributed to her low self-esteem, and I wonder how much isolation Hailey experiences as a result.

I have a lot less self worth and um like self esteem, because I feel like I’m not a fully functional human and just like people wouldn't want to be friends with a mess like me with so many issues […] They know that it's different and that there's a lot that's going on with me that they don't know if they want to deal with because they would rather just talk to other normal people, you know?
Hailey experiences numerous limitations because of her chronic pain and seems to see herself as less as a result. While she tells she is the top sales employee, the effect of her disability still pervades her self-worth at work.

I see myself as less worthy of love and just like less worthy than anybody else who would be working at [name of workplace] […] I still can't go on ladders because I pass out too easily and some days I just can't do that I’m. So like there's just little things like that that I can't do that somebody else could do it's like somebody else could do everything, including what I’m good at, and the things I cannot do because of my disability.

Hailey feels less deserving of therapy because she is not able-bodied, and the effect of seeing herself as broken is significant.

when I’m in therapy groups, for example, and these groups take like three months to get onto the waiting list and then there's only eight people and finally, like I’m there and it's like damn, somebody else should probably have this ‘cause there's like no hope for me, you know […] People that just are more deserving of that chair, because they're struggling too, and they could get farther than I could, being like able bodied and everything.

I wonder if years of dismissal have shaped Hailey’s self-doubt of her own pain. She tells me she sees herself as:

Dramatic. I feel like a hypochondriac or that most of the things that I’m struggling with are just like psychosomatic […] I mean, I cannot be sure of whether I’m even telling the truth or not […] And for my pain it's like, am I faking this? No, this is just bad because I’m treating it like it's bad and honestly, I’m still not at a point where I can say no, this is actual real pain.

Constant pain and negative self-esteem seem inseparable from Hailey’s body image. In our last Zoom meeting, one of the first things Hailey told me was, “I look really gross right now, because I’m in a lot of pain.” I wonder what dominant narratives have created this internal belief in Hailey that increased pain equates a “gross” appearance.

Body image in general has always been butchered and I think that on days where my pain is worse, I feel worse, maybe also because I don't put as much effort into being good-looking like I won't get out of my pajamas, won't shower if, like for two days, and I won't put on any makeup like if my pain is worse. And sometimes I have to go to work when the pain is really bad and I’ll try to do a lot of makeup just to feel kind of a little bit better, even though the pain’s that bad.
The association between perceived appearance and pain goes beyond being able to look a certain way, however:

The worse that my pain is, the worse that my body image is [...] it’s just like, I feel like a sack of rats and I don't feel very attractive with that kind of discomfort and pain.

I wonder how much Hailey’s sexual trauma exacerbated, and accelerated, the development of her eating disorder, fibromyalgia, anxiety, and depression, which led to further dismissal and stigmatization. Hailey’s internalization of other’s narratives struck me no more deeply when she uttered, “looking at this story right now, it's like why would anybody ever love me, would want this?” I asked why she felt nobody would want her. She elaborated, “just like everything. All of me. And the way that the physical and the mental health collides.”

Looking forward, Hailey describes worries about accelerated aging, loss of mobility, and worsening pain. Another fear Hailey divulges is death by sepsis.

I have so many UTIs, I- I’ve been on so many antibiotics and already immune to quite a few and, like, I say this as a joke, but it's honestly a rational, like pretty rational fear, that I’m going to die of sepsis at a pretty young age, because I’ll be immune to so many antibiotics. I’m just worried about like my health deteriorating too quickly to be able to do what I want in life [...] 

She tells me, “I mean that like paired with the fibromyalgia and trauma it's like, is there hope for me though?” I ask what keeps Hailey here. “Mostly people,” she replies. People who may not be in her life if not for her fibromyalgia. People she would not have met if not for her hospitalizations. Perhaps she would not have met Lucas if she had not self-harmed in grade seven. Hailey is making progress in small ways and shifting the way she copes.

I’m also 18 and I gotta take things a step at a time so I try not to overthink my future that much [...] for me it's just so unsure that I could have kids [...] I kind of accept the fact that there's not much I can do other than taking everything a step at a time.
Chapter 5: Megan’s Narrative Account of Living with Chronic Pain

My life would be easier were I not in pain, but it is still a life worth living. Being disabled is a part of who I am. It gives me insight into how important my health and my body are. It has influenced my maturity, my personal insight, my resilience, and determination.

-Megan, excerpt from medical school application

I see Megan as a calm and intelligent 25-year-old woman. She has lived with persistent pain since age 12, her first diagnosis being adolescent idiopathic scoliosis. In adulthood, Megan was also diagnosed with adenomyosis\(^\text{16}\), endometriosis\(^\text{17}\), and attention deficit hyperactivity disorder (ADHD)\(^\text{18}\). Scoliosis is the cause of most of Megan’s pain, defined as a deviation from the spinal axis with a spinal curvature of more than 10 degrees; adolescent idiopathic scoliosis refers to scoliosis with an unknown cause that is diagnosed between the ages of 10 and 18 (Troibisch et al., 2010).

I see Megan as strong, but in a quiet way, with a serene wisdom about her and an acute awareness of her strengths and shortcomings. She doesn’t wear make-up. In addition to being a “big cat person”, she describes herself as “anxious but very confident”, “academically minded”, and “a science person”. What I appreciate about her is her subtle feistiness, exhibited in her go-to response to someone else’s judgement when retelling her stories. She would often say, “that's a you problem”, or, “that’s a them problem if they’re not okay with that.”

While officially graduated, she was finishing work related to her graduate science degree when we met virtually in the summer of 2021, as her graduate work had been

\(^\text{16}\) Adenomyosis is a uterine disorder where endometrial cells (cells that line the uterus) grow and extend outside the uterine lining into the myometrium (muscles of the uterus), and can cause heavy, prolonged, and painful menstruation (Vannucchi et al., 2019).

\(^\text{17}\) Endometriosis is the most common cause of pelvic pain in women and refers to when shed endometrial cells (cells that line the uterus and are shed during menstruation) build up outside the uterus in sites such as the abdominal cavity, ovaries, fallopian tubes, or the lining of the pelvic cavity (Bulun et al., 2019).

\(^\text{18}\) ADHD is a neurodevelopmental disorder characterized by difficulty paying attention, impulsivity, and hyperactivity (American Psychiatric Association, 2017).
interrupted by the COVID-19 pandemic. Insightful and articulate, I found our interactions rife with her natural ability to balance logic with intuition; furthermore, though sometimes dark, our conversations tended to be full of laughter as we looked back on some of her past experiences and theorized together why certain narratives exist.

We met in the summer for weekly Zoom conversations, most of which were held in one of several record-breaking heat waves in the province. Interruptions were not infrequent as her cats entered the screen, begging for attention. Our first meeting, she declared herself to be in the “post-grad blues”. She was teaching a university course and deciding what to do in the fall.

Megan would wear white, oversized earphones for our Zoom meetings, and each meeting, I could see glimpses of the bright apartment she shared with her boyfriend, always a view of their balcony. Even when the blinds were closed, a sunny haze would shine through and I could see a folded patio chair through the window, tucked away on the balcony. Their apartment was on the 32-nd floor, and I could make out various downtown buildings through the window behind where she would sit – that is, when the wildfire smoke that gripped us for much of the summer would allow.

“My Life is Over”

Megan grew up on a small acreage outside of town. Immersed in farm life at her parents’ and her grandparents’, Megan spent a fair amount of time outside as a child, with cats as a constant from early on. She described herself as both defiant and independent from an early age.

One time, when I was like three I was playing around the stove and my mom’s like, “don't touch the stove it's really hot”, and so I stared her right in the eye and put my hand on the stove. That was very much what I was like as a kid [...]

Megan grew up dancing and skiing, but as her pain worsened in high school she was no longer able to participate at the same level. Well-liked by her teachers, Megan describes her younger
self as precocious. She experienced an unusual level of freedom, although denies being considered troublesome, except with her parents.

I would be allowed to get away with things that other kids weren't allowed to get away with, so it wasn't like, like I wasn't a troublesome kid except for my parents, you know, I didn't listen to them, argued with them a lot, very headstrong you know, independent, fighting back against their authority, especially.

Megan remembers the day that her pain started.

One morning, when I was 12, it was towards the end of the school year. So, I was in grade seven, I think. I woke up and my back was in such a bad spasm that I couldn't get out of bed, I was just kind of like laying there. And my mom was like “okay get ready,” you know, but I just- I wasn't getting out of bed, and she came in and she's like “why aren't you getting ready” and I'm like “I can't, I can't move, I'm stuck in bed.” So, she took me to the emergency room that day um and we went in and the emergency doctor knew right away that it was scoliosis. […] I remember, I was not wearing a bra, so I didn't want to go back to school after.

She doesn’t recall her pain significantly affecting her until late teen hood, other than having to sit out activities due to pain.

It just kind of became everyday like normal very quickly […] it was never quite the same like level of spasm that was just the one morning I woke up like that, but it was always just like a little bit of back pain here, you know. You know, especially when you're a kid you're out exerting yourself and then you know I'd have to sit down and like calm down a little bit […]

Being treated differently by her peers, she began to avoid explaining why she would need to sit out activities.

I was treated a bit differently. I mean, I had a brace right for a few years, it's kind of hard to be the girl with the brace […] I do remember like when I was younger, you know if I was talking about I’m in too much pain to do things like my friends would give me a hard time. You know, like they'd be like “ah, you always are in too much pain let's play and stuff” and then like I’d feel guilty about it and so either I’d like try to push through it, or like you're like “no I can’t” and then they’d be like “Oh, you know you're boring” […] then I kind of like tried to avoid explicitly saying it was pain that was causing me to like not want to do things as I got older I think kind of because of that.

19 Megan wore a custom back brace for approximately one year to prevent the lumbar and thoracic scoliotic spinal curvature from increasing during adolescent growth. The brace is an external support that applies pressure to the spine and ribs to prevent progression of a scoliosis curve.
At age 12, it was difficult for Megan to comprehend what it meant to have scoliosis. Without fully understanding what the diagnosis or possible surgery meant, as a 12-year-old, Megan imagined the worst, and I wonder how this affected her psychosocial experiences with pain later in life. Megan said:

I was upset [...] especially because I didn't really know what it meant, so I like kind of like catastrophized all these like, how terrible and I'll never be able to like ride a horse again, especially [...] I knew that you get rods strapped to your back and you might not be able to go on roller coasters or ride a horse ever again, and these are like devastating things to me, even though I never really rode horses or anything but like I’ll never be able to ride a horse, you know, very like, “My life is over” [...] 

The Scoliosis Clinic: “Like He Wasn’t Actually Looking at my Whole Life”

Twice a year, Megan and her mom would drive several hours to the scoliosis clinic. At the first appointment, Megan’s mom asked about having Megan do exercises. The physician’s response was, “No, she’s a girl, we only usually do that for the boys.” Megan had also been told by the physician that scoliosis doesn’t cause pain.

And then the other thing she had asked at that time, like, “Is there anything we should be doing to manage pain?” and at that point he had said, “No, you know, pain, isn't a thing that really happens with scoliosis.” And then that was, I think, so that was like the first few meetings and then later on in that later meeting, where he does mention the pain in the notes at that point my mom said, “Okay so she's in pain, you know, what should we do?” and he had kind of said again like scoliosis doesn't cause pain so what's probably going on is because she was in the brace her core muscles have kind of like weakened and so that's why he said to do core work, because I was in the brace.

This conversation stands out in Megan’s memory: “I remember that because she was so angry about it. I think that was my second appointment probably,” Megan said. As a dancer, Megan described that she had strong core muscles, and the physician’s response made her feel both dismissed and not understood:

But like it doesn't make sense, because I was a dancer and like I was doing like crunches on the regular as part of my dance stuff. So, like it was almost like he wasn't actually looking at like my actual life, because if he did, he'd know that I had decent core strength from dancing and stuff.
At age 12, Megan seemed to know her own body, despite the dismissal she experienced.

I was still like young um and so I knew scoliosis caused pain. But he was very much like it doesn't. Same with we’d ask things like is there exercises I should be doing to help keep my back strong and he's like “well you're a girl, so we don't usually worry about it, we have the men do the exercises, girls we don't.”

As she recalled this experience, I asked Megan if she was taken aback by this comment at the time. “No, I kind of accepted it,” she told me. She offered to send me her clinic records, and in reviewing them, I found Megan’s stories did not align with the clinic charting that stated she had no problems or complaints (for example, see Figure 1 and Figure 2). As I read through Megan’s clinic notes, each entry and clinic visit recommendations seemed focused solely on the physical aspect of her condition, not her pain.

Figure 7: Second Last Scoliosis Clinic Visit
Figure 8: Last Scoliosis Clinic Visit

In childhood and adolescence, females are more likely to have scoliosis with spinal curvatures greater than 20 degrees, which is when bracing is recommended (Troebisch et al., 2010). Megan’s clinic records were succinct, typically only stating the degree of her spinal curvature, chronological bone growth, and number of hours braced. Megan would reference the degree of her spinal curvature at certain ages, and I interpreted these as signposts to the progression, or regression of, her care.

I was braced to try to prevent it, but they had taken off the brace after like a year because they had decided that my bones had grown too much as it was, and so there was no point in bracing me anymore. And so before that I was at like 30ish\textsuperscript{20}, and so they took off the brace but then the next time they saw me six months later, I had jumped quite a bit in my curves so it almost suggested that they were wrong to take off the brace because it then deteriorated quite quickly after that.

\textsuperscript{20} The curvature of Megan’s spine was measured and recorded at each scoliosis clinic visit. Before Megan’s brace was removed, her scoliosis curve was 30 degrees. Megan is referring to an increase in the scoliotic curvature when she says, “I had jumped quite a bit in my curves,” indicating her scoliosis had worsened.
I see disconnections between Megan’s recollections and that of the physician’s charting. Megan is charted as a “good brace wearer” in the clinic notes, but Megan remembers the opposite.

I didn't think I was a good brace wearer, I would like sneakily take it off all the time and not wear it. Like I’d pretend to wear it to bed, because it was not comfortable […] so I’d only ever really wear it when like my mom was watching me, so I didn't think I was a good brace wearer and then it was weird for me years later reading “she's a good brace wearer” when I knew I was not.

The clinic notes in December 2010 state, “no problems, see in one year.” A year later, the only words charted in the clinic visit note are “no complaints”, though Megan tells me that this was when her pain was increasing and becoming more severe. The charting remains focused on the measurement and not the pain itself. I am drawn to the disconnect between Megan’s experiences with her physician and how her physician documented these patient-physician encounters. I ask Megan where this communication breakdown might have occurred.

I think he saw like 100 kids a day. So, like he’d come in for like you know, do the quick measurements and then like leave, like there wasn't really a chance to talk to him at all. Megan’s mom managed her care until she moved out at 17; because Megan’s mom was responsible for her care, Megan felt information was not explained to her adequately by health care providers, and there are gaps in her knowledge now when asked by physicians about her medical history. She tells me she felt let down by the health care system as a result.

[…] especially when I was younger like the doctors didn't really explain things to me, you know, like my mom took over the appointments a lot, which is understandable, because I was 12 but like. Things were never really, I was never really, explained what the next steps were going to be, you know any of that kind of stuff it was kind of explained to my mom and then my mom would interpret it for me. […] And so, even now, like doctors will ask me questions about like things that were told to me or plans that had been made for me back then and I never really remember […]

Megan remembers the scoliosis clinic as mainly a negative experience, with much of her frustrations centered around lack of time and communication with the physician. The appointments were short, with few opportunities to ask questions.
\[\ldots\] the doctor’d come in, he’d do his measurements, talk to my mom for like two minutes and then leave and so anytime my mom had questions she had to basically like drag him back to the room and be like “hey we don't know what's going on”, like you know, so there wasn't a lot of like communication from the doctor about you know, what to expect, what's normal, what's normal not normal.

Megan remembers being surprised when she was discharged before her sixteenth birthday, and she describes her and her mother being frustrated that next steps were not discussed. “I was kind of just let to go […] it's not a very like good experience for patients.” Megan recalls:

I remember that day. He came in, he did his stuff and he's like “Okay, well you're good so you don't have to come back” and we're like, we had to like chase him back from the door and be like “What happens now?”. He was so surprised by it, it was like… it's not like it's going away, like it's not like it’s a theatric thing that suddenly disappears when you turn 18. […] No one came and talked to me about like follow ups or stuff.

Looking at the clinic visit notes, two words, auto populated in a template, are all that indicate she was discharged that day: “Discharge – Y”, followed by “no complaints.”

**“The Pain got Worse”**

Megan’s pain slowly increased throughout adolescence. As she described, “...towards my late teens it started getting more and more of like a constant thing going on in my life.” At 17, she moved away from home to attend university; not long after, her pain worsened further. Attending lectures exacerbated her pain, and so she started skipping classes. Living on her own without her mother’s influence, she was also less active, and Megan shared stories of avoiding exercise because of pain. While inactivity initially improved her pain, it led to weight gain, which increased her pain because of the extra weight her back now had to carry. As she told these stories of pain and becoming physically inactive, I wonder how this period in her life may have been different if she had stayed at home for university. I asked Megan how weight gain, inactivity, and her physical pain affect her body image.
some of my weight issues are related to pain, because it's like hard to go and work out because I'm in pain [...] I do just dislike how much I weigh, I wish I was skinnier [...] part of that also does come down to you know I’m in pain so it's harder for me to work out and so it's harder for me to maintain a healthy weight.

Early in her undergraduate degree, Megan rolled her car while driving back to school, after which, her pain increased. “That could have been part of the cause, I never actually thought about that until now,” Megan told me. She remembers the accident:

I was sore but I blame a lot of that on, I was on a backboard for several hours. Like it was like three or four hours - no four hours, at least on a backboard. […] I have scoliosis so it's like even more uncomfortable […] it did start to get worse around that time, so it could have been the car accident.

She went to counselling for acute post-traumatic disorder following the accident but didn’t talk about her pain.

I went to counseling once because I got in a car accident, and I was like having a little bit of acute PTSD [...] but we didn't really talk about my pain ever it's not really something that's ever come up.

Megan told me her second year was the most difficult year of her undergrad. “I’d just been in my accident so like I was like super stressed all the time,” she said. Her living arrangements at university also changed last minute to renting a room in a house with two men in their thirties. Combined with post-traumatic stress and more difficult classes, her pain worsened.

I wasn't really comfortable in my home. And I was like always doing like this, like the fundraising [sorority] stuff and second year was like harder, like the courses were harder […] after the car accident […] I was having like trouble sleeping […] I was very anxious all the time that's the first time I actually went to talk to someone about my anxiety because I was like having like full on breakdowns in the library and stuff.

“Worst Pain I’ve Ever Been in”

The increased pain Megan experienced in her undergraduate program persisted into graduate school. She was nearly finished her graduate degree when the COVID-19 pandemic struck. According to Megan, the combination of lockdown and
increased stress cultivated severe pain related to her scoliosis. Furthermore, Megan was unable to access massage therapy for two months, a therapy which is an important aspect of her pain management.

[...] at the beginning of COVID like when massage wasn't open and like everything was shut down, it was like literal hell. Like that was the worst pain I’ve ever been in like because I couldn't go to massage and like I was just trapped inside [...] I was just in so much pain like I’ve never been in that much pain before it was just, it was so hard.

Uncertainty around her research during COVID-19 increased muscular tension and further worsened her pain. Megan described the cycle of tension, stress, and pain:

[...] I was trapped at home, so I wasn't out and about moving and so you know when you're not moving you get stiff and stuff and then I couldn't do massage [...] so it kind of got worse [...] there was also a lot of stress for me at that point because you know I wasn't really sure what was going to happen with my master’s, because I was in the middle of experiments and they all got shut down. [...] And so it's like well, what's going to happen now [...] I carry a lot of tension in my body, so I was like just tense and so just kind of this perpetuating cycle of like tension and stress and not being able to let it out and then causing pain and then that pain causing stress and tension [...] so it was just kind of perpetuating.

Before the pandemic hit, the lack of ergonomics at her desk and in the lab had increased her pain.

I didn't have a very good desk. Sometimes I’d like lay on the ground, under my desk, because it was more comfortable and I’d like bring a heating pad and kind of lay under there because my back was killing me [...] like the pain level was pretty high.

Too anxious to ask for accommodations, Megan continued repetitive lab work until the pain was too severe to continue.

I didn't tell my professor about it until I was like having to lay on the floor because I was in so much pain so [...] during my master's one of the things I did was I did brain slicing. You kind of have to like hunch over this little like blade and it was very hard on my back and so. I was also very anxious about asking to [...] have someone else do it for me [...] I did ask for it during my master's just because it was becoming unbearable [...]

Megan had idealized hospitalization in high school, and she also idealized hospitalization in graduate school. Unlike in high school where it would be related to scoliosis surgery, this scenario involved a car accident:

Sometimes during my master’s I’d like half; like not seriously but somewhat semi-seriously be like maybe I could get hit by a car today, and then I can spend the day in the hospital and not have to work on my master’s. And then I’d just like fantasize about emailing my professor, “Sorry I got hit by a car, I can't come in today.”

She tells me hospitalization would be a vacation from the pain due to analgesics she would receive, as well as:

A vacation from like everything. Yeah but, like, I think the pain is kind of tied into stress, too, because stress makes it worse, too, so you know, being able to relax and stuff like that does still have that benefit […] I think it’s nice getting attention, you know.

Megan cites a car accident as an easier way to take time off because, “I don’t have to be the asshole for taking time off.” I wonder why Megan feels she would be judged for taking time off. Regardless, idealizing a serious accident as an escape seems tied to the pressure Megan felt to work continuously.

[…] it's not necessarily self-imposed because the environment definitely like pushes it on you, but no at no point was I ever told something like that […] it was just always assumed that I was always available on weekends and evenings if I had to come in, and you know.

I wonder if this pressure originated in narratives that Megan should push through pain to maintain productivity.

with chronic pain I’m supposed to like work through it, and live through it […] you’re not allowed to stop just because you have chronic pain. And it's not visible so it's not like suddenly one day it's like there’s this black aura around me and everyone's like “Oh no […]”, like I look the same day after day.

With less-than-ideal work-life balance in graduate school, Megan was confronted with reshaping her imagined future.

All my life I was like, “I'm going to be a scientist I'm going to study neuroscience” [...]. And then I realized I didn't like that [...] I don't want to have, you know I'd email my
professor at two in the morning and he’d email me back right away, I don't want that to be my future you know. I want there to be a clear line between my day at work and my day at home [...] so I think I'm having that crisis that most people have in their teens now because now I don't know what I want to do [...] 

After finishing her master’s degree, Megan moved back to her home province. She began settling into a new city with her boyfriend; during the transition, Megan applied to medical school. When writing the application, Megan questioned how she would be perceived for disclosing her disability despite application guidelines indicating they value diversity.

But then it's always like well, you know, are they really truthful about saying they value it, will this have a benefit for me? You know, will it not have a benefit for me? and so it's like, something I struggled with like when I was applying for medical school [...] one of the things they talked about is like, you know, talk about your experiences and how it makes you fundamentally who you are, and I was like well do I talk about my disability? You know, because in theory, it makes me more like, it might make me a more exceptional doctor in that I have that understanding, but then is this person going to understand it, like the person reviewing my file, are they going to accept that?

In the end, Megan decided to write about her pain.

It was the first time I like talked about being like upset by having been diagnosed like about having, becoming moody and stuff [...] I like wrote about it because it is overcoming something, and they are supposed to try to be more like inclusive in that way, and so I did write about it ultimately [...] 

I wonder why this was the first time she wrote about her diagnosis experience, and how it affected her overall pain experience and journey. Megan told me she was worried about how her application would be received, but because she was offered an interview, she knew it had been to her advantage to reveal her pain experience. An excerpt from her application reads,

It has been very draining both physically and mentally to be in chronic pain since my early teenage years, and to know that it is likely to only get worse as I age. Because of how difficult chronic pain can be, it was important that I developed coping skills. I have learned to recognize situations that would exacerbate my pain and to avoid them, and I have learned how best to help to treat the pain. Additionally, to help with the mental difficulties, I have cultivated a strong support network. I believe that my experience as a disabled young adult will help me to make informed and rational decisions because I have a perspective on life and health that most able-bodied people do not have.


**Experiencing Health Care: “It's a big Concern of Mine That I Just Won’t be Believed”**

Megan describes a strong fear of being labelled as drug-seeking, malingering, or not believed and these fears shape her behaviors as a patient.

[...] I don't want to come off as knowing too much, because then I might be dismissed, you know. So like I’m always, especially with you know, doctors I don't know I’m always really cautious about [...] making sure that I downplay like my knowledge of you know pain medications and my knowledge of stuff like that, and making sure I downplay my pain a little bit so it's not seen as I’m drug seeking [...]

Having an understanding of her father’s experiences accessing care have shaped Megan’s perception of health care as a chronic pain patient and contributed to this fear of being labeled as drug-seeking by health care staff.

[...] one time he made the mistake of going to the emergency room and saying “yeah I need a toradol shot” and then instantly it was like “ah, drug seeker!” so he did not get a lot of care. And I think like the nurses like basically ignored him until his doctor who was the emergency doctor at the time came in and saw it was him, and it was like “Oh shit like this is real” and so the doctor ended up giving him his personal number and was like if you ever need to come into the ER, call me first, and I’ll tell the doctor on not to you know, treat you like that [...] 

Her early experiences of dismissal at the scoliosis clinic may have also shaped her view of health care providers and how women are treated. As a result, Megan feels she was not cared for adequately.

I feel like my pain was dismissed but also like wasn't even something that was acknowledged [...] like women are not really told what to expect with their bodies and stuff and I think that extends to the pain to like I wasn't really told what to expect or how it would influence my life or anything like that so like I had to kind of figure it out on my own and try to try and find that, on my own, and so I feel like a little let down from the medical community [...] Like especially before I kind of had my scientific background that I have now and I understand more about it, it was just kind of like I felt like very like not taken care of in the way I should have been

Megan’s own experience of dismissal during her early years living with scoliosis, combined with stories of others’ dismissal, have shaped how Megan experiences medical visits now.

I had heard stories from other people about like you know doctors who are dismissive especially to women, and especially pain and stuff and so you know I feel like I’m very
like I feel very protected when I go into the hospital and talk to doctors and stuff and like make sure that I come across as like respectable enough [...] women's pain is less believed and is more like thought to be like mental issues and, like emotional problems not like physical problems um, and so I think that impacts me.

Fearing dismissal, Megan recalls her experience telling her family physician about a new pain:

I was like a little worried, well, are they going to think that I’m making it up [...] so I’m always like nervous around doctors [...] I’m not really that nervous with like non-doctor non-nurse people, though, like, anyone who does like massage therapy or physiotherapy [...] I’m never really as worried that they’ll be like dismissive [...] Gender is a factor, as well, and Megan prefers female doctors over male doctors.

studies show that female doctors have better patient outcomes [...] I feel like there's more asshole male doctors than there are asshole female doctors, which might not be true, but I think it's like my own personal, cultural perspective.

Megan’s scoliosis doctor was male, as was her family physician from age 10 to 14, who she described as “not very understanding.” Megan reports she has a good family doctor now:

She believes me. Even things that like she doesn't necessarily think are a big deal she's still like, “This is probably okay, well, let's get it tested anyways just to make sure it's actually okay.” [...] it's really important for women who have doctors who actually care about things like mental health and women's health [...] rather than just dismissing you out right in the first place.

Needing permission to address pain, however, is a recurring thread for Megan:

[...] like my doctors recently have all been good [...] I know if I wanted to talk about pain management stuff with them, I could, and I could make plans, but I almost feel like I need permission to do it, I don't know.

I wonder how this narrative originated – was it a family narrative? Was it because of her experiences of dismissal at the scoliosis clinic? I wonder how it affects her pain experience, and how it relates to her belief that she is expected to self-manage her pain without complaint:

I just don't feel like I should be complaining about my pain, or like looking for solutions to it like it's something that I should just try to manage, I think. [...] I feel like I'm just kind of supposed to accept the pain I'm in, and I know objectively that's not true. But maybe, maybe it's because they've never actually like, like they know I'm a chronic
pain patient but they've never really like talked to me about my experience with it. I think they think I manage it well, and so they've never really like brought it up.

**Relationships**

As I spent more time with Megan, I began to understand that guilt is a recurring emotion for her, most often centered around her relationships. Her storied experiences of pain and disability were often nested within larger narratives around family and with her current boyfriend, Justin\(^ {21}\).

**Justin**

In the first week of her undergraduate program, Megan met her current boyfriend, Justin. Megan was open about her pain with him from the beginning, and felt he was understanding and supportive. She described the time that she first disclosed her pain to Justin as unceremonious. “It was like, ‘Oh, my back hurts’ and he's like “Oh, why does your back hurt” and I’d be like, ‘Oh well, I have scoliosis,’” Megan said, “when it came to like the pain and stuff he was never, like, never made me feel like I couldn't say I was in pain or anything.” When they were first dating, Megan would agree to go on dates even when she was in too much pain, but not because she felt pressured to by Justin. I wonder why early in the relationship she felt the need to push through her pain even though she felt Justin understood her pain. I asked Megan why this was:

> […] he’d invite me out on a date and it would be more of a thing at the time, right? And so you know, even though I’m sore, I’d still go because I want to go on the date, whereas now you know it's like well you know we can always go tomorrow […] the relationship’s different when it's earlier, you know there's more like, like urgency to everything […]

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\(^ {21}\) Pseudonym used.
Justin is Megan’s first boyfriend, her first sexual partner, and her first live-in boyfriend. I asked Megan to imagine what her life would have been like if her first and only boyfriend was not so intuitive and understanding of her pain. In my interactions with Megan, I never observed evidence of her anxiety, and so I was somewhat surprised when she responded:

Well, I don't think I'd still be with him for one. But I think it would have also like have made me more of an emotional nervous wreck. Like I, I'm kind of an anxious person to start with, and he helps like tone it down. Whereas, if he had like, had made me feel more guilty or like more put more pressure on me I'd be more anxious, I think.

Pain with penetration during sex was occasional when Megan was first dating Justin, though she mentions still experiencing pleasure despite pain. Not knowing differently, Megan continued to dismiss the pain she experienced during sex.

I also like didn't really know what was normal or anything either, so I wasn't sure if you know it's just something to be expected, like, you know, when I lost my virginity that was a little painful but I’m like, “Oh well everyone's virginity is painful”, you know, that's what we're told in stories, not realizing that it doesn't have to be that way.

I asked myself, how did pain with sex become normalized in Megan’s stories? I wonder what stories Megan means by this, and where they came from. Were they stories she learned from peers or teachers at Catholic school? Or did she learn them from her mother?

Unfortunately, as Megan continued to ignore the pain with sex, it worsened. In addition to scoliosis pain, she described uterine pain, pain with penetration, and medication side effects that impacted her sex life.

Cymbalta just killed my sex drive, and so I became so anxious about it, because at the time it was like harming our relationship a little bit you know because he was like not happy with the amount of sex we were having, and so I was like “Oh, we need to have some more sex, but you know I’m not interested” so, then you know I tried to have sex when I wasn’t ready and then I’m like oh this isn't working and then it just kind of like yeah perpetuated after that. And then you know, of course, you have pain and then you're like anxious about having it again, and so it gets worse and it kind of it's a never-ending kind of feedback loop.
Besides anxiety and pain around sex, Megan experiences guilt for not having sex with her partner, which she related back to her Catholic upbringing.

[...] you know it's not your fault, you know your partner loves you, but like subjectively you like feel [...] I was also raised Catholic so it might be like Catholic guilt.

**Family Narratives: “You’re not Disabled”**

Megan’s stories often reference guilt in relation to her Catholic upbringing, guilt that also seems to manifest itself in her family relationships. When Megan was nine, her father was in a serious car accident, and he developed myofascial pain syndrome.\(^{22}\) Knowing how her father managed his pain helped Megan to learn how to manage her own pain. Consequently, since one of Megan’s few real-world benchmarks was her father’s pain, she experiences guilt when comparing her pain to his:

sometimes I feel guilty, though, because, like his is so much worse than me and like I feel like I don't have an excuse, because you know his is worse, so I shouldn't be like complaining.

“I feel like I'm expected not to complain,” Megan tells me. Through Megan’s stories, I can see how familial narratives have become internalized. Her mom was constantly busy and expected others to be the same way, even if Megan was in pain, and she tells me her grandmother was the same:

I’ll be like I'm in too much pain and she's [Megan’s mom] like okay, well, it needs to be done so do it anyways you know. [...] Like I mean she understood it was there, but I think she kind of. Like she's a very go-go-go person and my Oma (my grandmother), her mom, was a very go-go-go person, and so you know they, they don't really take breaks [...] so I think there was kind of that expectation for me too where like, even though it wasn't relaxing, it was me being in pain, it was like well you know, there's still stuff that needs to be done so you're gonna have to do it anyways.

\(^{22}\) Myofascial pain syndrome is a pain condition where muscular tension and pain related to trigger points occurs.
In her early twenties, Megan began to accept her own disability. However, her mother was not as accepting, which Megan sees rooted in protection:

I’m more, like, understanding and accepting of the fact that I am a disabled person. It took me a while, I think, to get there, especially because my mom was very like, “you're not disabled”, because in her mind again, like in her mind this was to protect me because, if I was disabled, then, you know, people would look down on me forever and stuff but, and so it took me a while to accept, you know what? I am a disabled person and that’s okay.

To me, her mother’s lack of understanding around her disability seems to come from intergenerational narratives and a lack of lived experience with pain:

Like unless something happened to her [mom] and then she was forced to slow down I don't think she will, she’ll ever understand. Like and even her mom is still like that [...] And so it's not that she wasn't supportive she just fundamentally could not understand [...]

I wonder if Megan’s ideas about gender roles came from these family narratives, and the belief that:

[...] women are expected to still do things like you know when you're sick you're still supposed to manage your house and when you're like if you have kids you know you're still supposed to take care of your kids.

Megan has always felt a strong sense of responsibility for her younger sister, who has autism spectrum disorder, and her mother’s expectations for Megan contribute to this sense of responsibility. In Megan’s fourth year of university, her parents bought a house for her and her sister to live while attending university.

She [sister] moved in with me when she went to university, and so there was kind of this assumption that I would be a support for her, but I also think my mom kind of has those expectations of me for her.

She described not being the “best” sister as a child and is trying to be a better sister now. However, Megan feels like being a support for her sister can take its toll, and she mentions how the stress and anxiety that results from this responsibility can increase her pain. Acutely
aware that she is an important support for her sister, Megan does her best avoid ‘burdening’ her sister with her own pain-related challenges:

I’m a really important support system for my sister, and so I don’t want to put my own problems on her, you know ‘cause she has like she has a lot of problems with her autism. And like you know, depression and stuff like that, and I just don’t want to burden her ever with it because I’m her support.

One night, Megan didn’t answer her phone. Her sister was in crisis, and this is a strong memory she has not forgotten.

I get anxious and stuff if, like my phone is turned off because what if she calls me or something […] I felt really guilty about it for a long time and lots of anxiety about not having my phone with me and not being able to answer her if she calls and stuff.

Managing her own needs with that of her sister’s is a balancing act affected by Megan’s pain experience:

I don't know if it's necessarily my pain, but like when I have my own things going on and stuff like I get really annoyed at her neediness. It seems she’s always neediest when I’m like busy, you know? And then, like, like I’ll be snippy with her, and then I feel bad because if I’m snippy […] it's like, this weird balancing of like trying to still be supportive while still being able to make my own things happen and stuff.

Having attended Catholic school and being raised in the Catholic faith, Megan adopted many of the same religious beliefs for a time. Megan shared stories that pointed to the secrecy that surrounded the female body, and she describes how her Catholic schooling contributed to this lack of knowledge around the female body:

I had this realization like when we were younger, you know we, I was, went to a Catholic school, so there was like this kind of like pro-life attitude that was taught […] for me it made sense because it's like “oh yeah, you know, […] you carry the baby and then you give birth and it's fine,” but then like as I got older I realized, “Wait. Like pregnancy is a serious thing that happens and it's like has huge long lasting effects on your body and stuff” […] this is almost kept secret from us until like we need to know […]

As she grew into adolescence, she navigated what was considered normal or abnormal about the female body, which left Megan to discover many of these mechanisms on her own.
so much of [...] the woman’s body is like kept secret, you know, like, I was thinking about this recently because I’ve been reading about like stuff that happens during pregnancy [...] 

I wonder in what context she felt the female body was considered secret: her family? Friendships? Social circles? I wonder if this secrecy around the female body began in her family stories, for Megan tells me that pain and other symptoms with menstruation were not explained to her growing up:

Like no one tells you “Oh, this is an acceptable level of period pain or, by the way, you know when you have your period, sometimes you get diarrhea because sometimes that's a side effect” like, no one has these conversations, and so you kind of just have to figure out on your own that this is not the normal everyday experience for women.

Megan shares her experiences of Catholic culture, and how blame is attributed to the individual. […] culturally there's kind of this thought that, like things that happened to you are your fault, too, I think. Like you should have done something different, and pulled yourself up more, you know?

I see how these institutional narratives of Catholicism, in addition to her mother’s narratives, contributed to guilt that Megan still experiences around her disability and anxieties. Megan describes her experience of growing up in the Catholic faith and how it has shaped her experience with disability and anxiety:

there's like this tendency for Catholic people to feel guilty about like their thoughts and stuff and guilty for everything like, like as if everything is your fault like […] Um I’ve definitely adopted some of it like I do feel, like some of my anxieties and stuff do come from that, but I don't know how much of it is necessarily like because I went to Catholic church and how much of it is necessarily because my mom internalized that, and so I internalized that […] it’s like an influence that definitely like played some part in like my anxieties and like guilt and some of that guilt does include around my disability […] 

Megan describes guilt when she feels sorry for herself for how chronic pain affects her life, and I wonder how much her Catholic upbringing has contributed to guilt and dismissal of her own emotions.

“I Said Normal People Before I Accepted That I had a Disability”
Identifying as disabled was a gradual process, and for Megan, it was ultimately defined by her limitations.

I said normal people before I accepted that I had a disability. I kind of think I was aware of the fact that this isn't normal, this isn't what most people experience. [...] and then it was kind of more later that I kind of accepted that, okay, that means no, I am disabled [...] I'd like read about experiences and then [...] got to thinking you know, the fact is, I can't just do everything other people can do, you know. I have to be conscious about the fact that I have limits and stuff and I have to be more aware of that, you know, whereas other people don't really have to think about that, and so I kind of just slowly started saying, you know what? If I have those limits, then that is a disability, and you know, that's okay. And kind of slowly moved there but it wasn't [...] instantaneous it was just kind of like a gradual acceptance of that's who I am as I got older [...] Four months ago, Megan’s pain improved significantly and at first, she thought something was wrong. “I thought, maybe it was... like I was sick or something or like I had a tumor maybe or something [...] because it's just, it's been it's been part of my life, since I was 12,” she reflected.

Megan tells me she is so accustomed to constant pain, that,

if I ever lost that I'd be a little lost, I think. It's not supposed to change. That's always been who I am and so it's kind of a part of who I am. And like, I almost don't feel comfortable if I’m not in pain, just because it's what I’m used to.

Because she received a diagnosis from the start, Megan tells me a scoliosis diagnosis “doesn’t really mean anything [...] it’s part of who I am [...] there’s nothing special about that diagnosis.” When Megan was a child, she believed she could think her scoliosis away; then, that the surgery would fix it. In her late teens or early twenties, Megan began to accept that her pain was chronic, and that her scoliosis would not be cured. As an adult, Megan was also diagnosed with adenomyosis, a diagnosis which had both less and more meaning than scoliosis.

to me that diagnosis [adenomyosis] meant more right, because, like we didn't know what the pain was and then now we have a diagnosis right whereas for the scoliosis like it's the starting point. [...] For me, you know, adenomyosis [...] that's something that we worked for, towards, to find whereas the scoliosis we knew right away [...] I think it'd be more different if I wasn't someone who, with chronic pain who then got the diagnosis so, like,
you know it has a meaning to me but it's kind of not – no, it doesn't really have a meaning to me either […] yeah, it causes pain, but it's not even my primary source of my pain like it's, you know, it's like something on top of it and it doesn't matter as much to me.

Her scoliosis diagnosis is integral to who she is, so much so that Megan says, “It's just who I am […] you know it's - I’m a person who has scoliosis, it’s like I’m a person with blonde hair or I’m a person who's X feet tall. It's part of who I am.” This ingrained identity as someone with chronic pain is so entrenched that she tells me she would continue to identify as being disabled even if she no longer was in pain.

I think I’d still identify as disabled, even if it went away, even though I would no longer be a disabled person, because I think it's influenced how I understand myself. And I don't think that would change, you know, I'm very aware of the fact now that at any moment any of us could be disabled. You know, anyone could walk down the street and then get hit by a car or something […]

A Constant Balance: “If I am out as Disabled then I Might get Discriminated Against”

Despite being a part of who she is, Megan’s disclosure of her pain and limitations are context dependent.

I’m pretty open with like people I know personally […] in that kind of setting I’m like […] that's a you problem if you have an issue with that […] As a rule, I don't usually say anything about my disability until I have the job. […] I don't want to give them a reason to discriminate against me […] I will not say about it at work, unless I absolutely have to.

In social interactions, considering others’ needs while balancing hers, she avoids explicitly mentioning her pain:

sometimes I don't want to bring the mood down by bringing it up, you know, so […] I’ll like kind of either try to like push through pain, or like, like slowly kind of sneak off and like try not to like interrupt the group so much because I don't want to like bring the vibe down.

Learning how to navigate daily with chronic pain is a constant balance for Megan, and deciding when and whom to disclose disability to is another balancing act. In the workplace, Megan is cautious about revealing her disability due to the potential for discrimination,
and I see how the dominant narratives around disability influence her decision around 

disclosure. Megan explains:

And so it's kind of like trying to balance these like cultural expectations of productivity and, you know, not being able to say no at work with my own needs and like that anxiety of like, well, you know, if I do say no, and I do say this is my limit, will this like affect my future job prospects? Will I get fired? Will my boss not like me? You know, will I not get time off when I need it? [...] and it doesn't necessarily even just stay with that company, it could follow you everywhere [...] 

Hiding versus revealing her disability is a constant balance, requiring careful consideration:

I can hide, but then I’m like putting myself out - like I’m pushing myself when I necessarily shouldn’t have to and stuff. And, but if I show up like, if I am out as disabled then like I might get discriminated against, and then I might lose job opportunities and so it's just, it's, it's hard, yeah. It’s like a constant balance of trying to decide whether it's worth talking about or not.

Megan’s fears of discrimination for disability are partially founded on the narrative that disabled people as seen as less competent.

[...] I think a lot of people kind of infantilize disability and don't really see it - as disabled people as competent, even though they are [...] kind of that image of like someone who can't do anything for themselves, when you think about disability.

The experiences of others with disabilities have also influenced Megan’s narratives of disability in the workplace. “I like to read, you know, stuff online about it [...] and I know that's what's happening for other people, and like so it could happen to me,” Megan tells me about being fired.

Fear of disbelief also saturates Megan’s fear of subtle discrimination and implicit bias in the workplace.

I’ve never been worried about people explicitly saying things like “Oh well, because you're in pain, you know we can't hire you” or anything but more like “Oh well, this is the third time, and she keeps saying [it] isn't because she's in pain [air quotations around in pain], but obviously she doesn't want to do this so fire her.” [...] even if they're explicitly like pro… supportive of people with disabilities, they might still have that implicit bias that like stops them from necessarily wanting to hire me, for example.

Megan speaks to how culturally, we equate health with goodness, as if the individual is to blame for their disability. “There’s like a moral aspect of disability,” Megan explained, reflecting:
I think there's like kind of this idea that like disabled people aren't trying hard and if we just tried harder, you know we'd be worthy like worthy of not being disabled and stuff and we're just drains on people and, like we're more like I think there's like this morality assigned to it and, like even if people don't outwardly think that like I think it's kind of like, like subconscious in how they deal with people with disabilities and like implicit.

Narratives about disabled people - both internal and external to the disability community - show this need to judge and compare disabilities. Megan echoed some of these cultural beliefs:

[…] ‘cause like you're not doing enough, and especially like people who are on like AISH and stuff and like “Oh, you know they're the bad disabled people who are taking advantage of the system and stuff.” And even like other disabled people sometimes things like that, like, I know of people who are on disability and they're like “Oh people on disability are just drains on society but not me I worked hard, and so I deserve this” you know and “I’m the real disabled person.”

In accepting accommodations, Megan considers both the level of resource scarcity, and the spectrum of disability, and I see how this leads to Megan doubting her own disability:

sometimes even when I talk about being disabled I feel like a little bit like an imposter because I don't - like I am disabled, it's very true, but like I’m not so disabled that I need some caregiver […] so, then you know when you try to talk about your needs as a disabled person it's like well, what about those people […] yeah, you know those people they might have it worse, but it doesn't still mean that I don't need accommodations and stuff.

Megan considers what accommodations are readily available in the context of varying levels of disability, before choosing to use an accommodation.

So I kind of like to think about like disabled accommodations is like things that are limited resources and things that have like unlimited resources and so like for things with limited resources […] there’s only like so many disabled parking spots that exist or like disabled washrooms and stuff […] where it's like unlimited resources, I think about things like extra time on exams right, you can give all of the students extra time on exams […] so I kind of try to balance like you know, I am only… I’m not as disabled as other people, so I try to reduce the number of like limited resources I try to take, but I don't have a problem with taking these kind of unlimited resources.

I imagine the constant evaluation and comparison of disability in each situation must be exhausting for Megan; another continual balancing and re-balancing. I can relate to Megan’s consideration of disability resources - sometimes I fall into believing the dominant narrative that
young equals healthy, and fail to ask for accommodations when I need them. What narratives place Megan in this position, where she has to consider if she is ‘deserving enough’ of an accommodation? I cringe at the idea of being “not as disabled” and therefore, somehow less deserving of disability accommodations. I believe that living out this narrative continues to marginalize the disabled by pitting those with disability against each other and themselves.

Megan’s stories about limited and unlimited disability resources also influence whether or not she reveals her disability. While disclosing means being seen differently, it increases awareness, and Megan contemplates this social responsibility to disclose:

But then, is that the right thing to do [...] because on the one hand, like if I show my disability and I talk about it, you know, maybe, people will learn “Oh, well, you know, she's disabled and she's able to do these things so...” Like you know, do I want to be the martyr or do I want to be like [...] the one who pushes against the system and, like might be rejected, or do you want to just kind of go with the flow? And like I’ve done both at times in my life, and you know it's like it's hard [...] Simultaneously, Megan worries about setting a harmful precedent for other disabled people given the spectrum of disability, and this determines how much she reveals about her disability:

[...] if I talk about me being disabled and then there's a different disabled person that comes along, what about the able-bodied people like, will they start saying things like “Oh well, this person was able to do that”, so you know, “you, who has more limitations, are lying” or something like that too right because I don't necessarily know what their intentions are going to be with stuff I talked about [...] With fluctuating pain levels, Megan worries she will be judged from one day to the next, including by herself.

And like I’m always worried like will my performance on the worst day be compared to my performance on the best day and then there's that judgment, you know, like, “Oh, you know I can't do this” and then they're like “Oh well, you're able to do that every other day” [...] every other day is different, you know, that’s not today and even being your own like pedestal you know.
Because disability presents on a spectrum, and for Megan hers is not visible, she struggles to feel recognized. Megan told me that sometimes, she wishes her pain was more severe:

sometimes the days that are like more painful are easier than the days that are less painful, because I have like a good enough excuse that I can just kind of stop my day and just sit there. So, like sometimes I'd prefer just being in more pain than in less pain, because then I can just say no, I can't do anything and then just go lay in bed all day.

When I asked why this is, Megan responded, “I don't feel like I'm allowed to […] I need to give myself enough pain permission to do stuff like that even though I know I don't actually have to.”

“This is my Future?”

Megan’s past and present experiences of pain influence what she imagines for her future, such as contemplating a time when life may no longer be worth living due to pain.

I think one day I’m going to probably commit suicide, not because I’m suicidal or anything but because it's just tiring to be in pain all the time, and you know, knowing that that's my future like it's not like it's something that's going to magically disappear one day it's just going to probably get worse, so I know that someday that's probably going to happen.

I appreciate Megan’s openness about a future that may not be worth living. In our first few meetings together, my professional knowledge screamed to assess for suicidal ideations each time we evaluated the future. My reflections on this encounter with Megan read:

My professional knowledge was that contemplating suicide is wrong; pain is treatable, and there are supports available. My instincts were strong: as a health professional, we must prevent suicide. Refer and assess for suicide risk. Make a contract with the patient. Call the crisis team. And yet, here I had to think about my position as a researcher. Do I not think about death at times, hoping that medical assistance in dying will become available for my own chronic pain should it worsen with age, and I no longer wish to exist? (Field note, July 23, 2021)

Several months after my last interview conversation with Megan, I was at my 12-month post-operative appointment when the surgeon said to me, “You are going to have so much pain and arthritis everywhere when you are older.” In response, I half-jokingly mentioned medical
assistance in dying as a solution to pain in my very distant future. The surgeon did not approve, and I learned of another story to silence.

I wonder how knowing the pain will worsen affects how Megan lives her life now. Megan’s imagined future is one where her pain becomes intolerable, and I wonder if her fears of aging are tied to anxiety around worsening pain.

I’m really anxious about getting old because I feel like, like being in pain and stuff happens kind of naturally when you're older so I’m like worried that it will just be like so much worse […] I’m just worried it'll be worse because I already have scoliosis and I know that it's going to get worse as I get older, so there's kind of like a question mark as to how much worse [...]

Looking forward, Megan has been confronted with a changed future and forced to rethink her future. In writing this chapter, I returned to my field notes to contemplate how pain shapes future identity. An entry reads,

Sometimes I think Megan, Hailey, and sometimes myself, in living with chronic pain and lost identity, attempting a way forward with a new yet old identity, will be living in the intersection between past and present identity forever. A liminal space. Chronic pain is fluid in how it affects your identity and what you can or cannot do. In this way, perhaps we are forever in a liminal space at the margins of the intersection between who we were, who we thought we would be, and who we were becoming. (Field note, September 25, 2021)

Megan tells me that living with pain, and having a sudden onset of pain at age 12, has made her believe much of her life is beyond her control.

Chronic pain has in fact affected me, I think I have more of an external locus of control because of it […] I feel like most of it is like out of my hands, because, like ultimately, like I could walk down the street and get hit by a car and everything I did doesn't matter and stuff and so […] it's hard to think that you have control when you're in chronic pain […] it's really something I can't control […] like all of us are so close to being disabled and we don't even know it right, and so I think it's really given me that, like, I can't really control my life perspective.

Having this external locus of control is not without negative consequences. “Sometimes I also feel like hopelessness, because it's like […] sometimes I’m like ‘Oh well, you know it doesn't
matter what I do you know. It's not like I can stop anything,’” Megan said. Without me prompting, despite her future anxieties and fears, for now, Megan asserts she is still happy.

my life is still worth living like I'm a happy person, you know but it's hard just being in pain, every day, you know, even if it's just you know, usually level two level three it's just like, still like, this is my future? Like one I'm gonna have to live with every day?’”

**Conclusion: “Who am I, and who, who is my Pain”**

Megan defines herself in relation to other people when I ask her to list her roles: daughter, girlfriend, sister, friend, student, teacher, citizen, and patient. She tells me she identifies as a patient “because I have like, I have not only my doctor, but my massage therapist and my osteopath and I see them very frequently like more frequently than I see some friends.” I believe her identity as an emerging adult woman with chronic pain is ingrained in each of these roles. Megan asserts that much of who she is would remain even if she was no longer disabled.

it's such a fundamental part of who I am I think you know, like even like habits and stuff I've picked up like I don't think they're going to go away, just because I’m no longer disabled.

This part of her identity is perhaps so indistinguishable from her pain that she tells me she would experience identity loss only if she was no longer in pain.

I’ve never known myself without pain […] I never really had the opportunity to know who I was without pain […] it's hard to know who am I, and who, who is my pain […] It's an identity almost for me like I didn't lose anything because I wasn't really like I was a person, but I wasn't really a person before, like I was a kid right. So it's more like I feel like I’d have more identity loss if I was no longer in pain.

Megan’s experiences and knowledge of others’ experiences - in the workplace, in relationships, and in health care - have determined many of her fears and behaviors related to living with chronic pain. As Megan revealed in her medical school application, living with chronic pain is part of who she is. At times, there is hopelessness towards future continuity, as she once wrote:
I continue to struggle with chronic pain, which can be difficult. It has been very draining both physically and mentally to be in chronic pain since my early teenage years, and to know that it is likely to only get worse as I age.

I think of Megan now when I catch myself absorbing or taking responsibility for others’. Their worries do not serve me. When someone disagrees with Megan or the way she is living in her stories, she would shrug and say, “That’s a you problem.” I hear her words now when I catch myself taking on worries that shouldn’t reside within me. I too easily embody worries that don’t serve me, and I recently echoed Megan’s “that’s a you problem” statement - and attitude – when encouraging my mother not to take others’ words so personally.

I believe that living with chronic pain has cultivated maturity, insight, resilience, and determination in Megan that is evident in her story, and how she defines herself in relation to others. There is a quote board in my living room that pronounces, “Not everything that weighs you down is yours to carry.” While these are not Megan’s words, I imagine it as another way to declare, “that’s a you problem,” and I wonder how long past our inquiry I will think of Megan’s words when I see this quote.
Chapter 6: Narrative Threads: Making Meaning Through Storied Lives

Stories nurture our connection to place and to each other. They show us where we’ve been and where we can go. They remind us of how to be human, how to live alongside the other lives that animate this planet. Just as Quakers believe no single person holds the whole truth, no one story can give us the whole picture. We need every voice to speak its version of truth from the silence. We need every story to guide our lives. When we lose stories, our understanding of the world is less rich, less true. Each voice lost, human or wild, erodes our knowledge of who we are.

-Susan Tweit, *Walking Nature Home*

In chapters 4 and 5, I retold narratives of living with chronic pain that Hailey and Megan shared with me. Stopping to reflect on my own experiences in this narrative inquiry, along with those of Megan and Hailey, I returned to the roots of narrative inquiry and began to construct this chapter. This chapter focuses on my further inquiry into the stories told by Megan and Hailey – looking inwards to the *stories to live by* (Clandinin & Connelly, 2000) that shape Megan and Hailey. By doing so, I began to notice and identify *narrative threads*, patterns or narratives that resonated across narrative accounts of participants, that I discussed with my response community (Clandinin & Connelly, 2000). Exploring these resonant threads in the context of time, sociality, and place, I began to understand how Megan and Hailey’s stories to live by have been determined by their experiences in becoming emerging adult women living with chronic pain.

Each participant’s life narratives are located in place: childhood homes, schools, hospitals, clinics, workplaces, places of travel, and places away from home. Narrative threads located in these places resonate across Hailey and Megan’s narrative accounts, bringing attention to stories of being silenced, making sense of their pain through relationships with others, and coming to identifying as disabled. In this chapter, I give careful attention to how these narrative threads have shaped Hailey and Megan, and how they story themselves. Returning to my research
puzzle, I examine how the dominant narratives of individuals living with pain in the context of age, gender, and disability have influenced Megan and Hailey’s stories to live by.

**Silenced, Invisible, and Locating Self with Pain**

Reflecting on the stories told by Hailey and Megan, narratives of being dismissed resonated across their narrative accounts, sharing experiences of dismissal over time determined by relationships with family, friends, and health care providers. Understanding this through the commonplaces of time, sociality, and place (Clandinin and Connelly, 2000), dismissal of their pain has often been experienced as a lack of information, autonomy, validation, belief, empathy, and equality. For Hailey, dismissal of her pain began as a child; she told stories of tough love and a lack of concern for her pain that evolved into self-doubt and experiences of being silenced in health care. Megan’s narratives of dismissal first emerged during her time as a child at the scoliosis clinic, a place that molded her early narratives of living with chronic pain. These experiences of not having their pain recognized or understood evolved through Hailey and Megan’s social, cultural, personal, and broader institutional narratives storied in spaces of family and health care.

**Family Narratives of Dismissal**

Experiences of misunderstanding and disbelief from family towards pain are common among emerging adults living with chronic pain and often lead to disruptions in family relationships (King et al., 2011; Kuehn, 2018; Palermo, 2000; Twiddy et al., 2017). Familial narratives shared by Hailey and Megan centered primarily around interactions with their mothers, who were their caregivers in their chronic pain journeys until adulthood.

When Hailey was officially diagnosed with fibromyalgia, her mother did not accept the diagnosis. In her narratives, Hailey made sense of these tensions as her mother wanting to do everything she could to find an alternate diagnosis for Hailey. Hailey storied experiences of
dismissal from her mother as rooted in intentions of love and protection: for not wanting Hailey
to live with fibromyalgia, which Hailey and her family understood at the time as “not a real
disorder.” Similarly, even when Megan began to accept her own disability, her mother did not.
Megan explained her mother’s beliefs that Megan would be “looked down on forever” in society
if she were disabled. There are tensions between how Megan stories herself as disabled and how
her mother stories disabled people, which, like Hailey, Megan makes sense of as her mother’s
protective instincts and an attempt to avoid her daughter being branded with the label of
disability.

Megan also shared narratives of her father’s experience of his own pain, and these storied
memories contributed to her own pain experience. Storied memories of her father’s pain being
more severe than Megan’s contributed to Megan storying her pain as less valid when compared
to others with more severe pain. Her father’s experiences accessing health care also altered
Megan’s own experiences when portraying herself as a patient, striving to avoid being dismissed
or labelled as a drug-seeking patient.

Growing up, Hailey and Megan were expected to continue chores and tasks of daily life
regardless of pain level. This shaped Megan’s expectations of herself into adulthood as an
emerging adult woman living with chronic pain. “I feel like I'm expected not to complain,”
Megan told me, and I observed the familial and cultural narrative that women are expected to
work through sickness or pain:

[…] women are expected to still do things like you know when you're sick you're still
supposed to manage your house and when you're like if you have kids you know you're
still supposed to take care of your kids. -Megan

Reflecting this social narrative, a significantly higher proportion of men living with chronic pain
are unemployed or on disability, yet women with chronic pain are consistently shown to
experience more severe pain in a greater number of body areas than men and tend to remain
employed (full-time or part-time employed or homemaker) (Bartley & Fillingim, 2013; Racine et al., 2014). Gender stereotypes may contribute to these differences, as men have traditionally been expected to carry out paid work whereas women have predominantly been responsible for unpaid domestic work at home (Lewis & Lupyan, 2020). However, women, but not men, report being expected to cut down on self-care activities when living with chronic pain, prioritizing their expected roles over pain management strategies (Samulowitz et al., 2018). This expectation may be compounded by the knowledge that unpaid domestic work carried out by women is often undervalued and unrecognized in the home, and not viewed as productive work (Guppy et al., 2019). This dominant familial and social narrative that women are expected to work through pain has affected Megan as an emerging adult woman who struggles to practice self-compassion and balance cultural expectations of productivity with her own pain management needs.

While Hailey re-storied dismissal experiences in her childhood as “tough love,” showing gratitude for her parents’ intention to foster independence, both Hailey and Megan re-storied dismissal experiences as rooted in protection. Megan also re-told intergenerational narratives that her mother learned from her grandmother – the need to continue working despite pain or illness. Making sense of who they were becoming as emerging adults living with chronic pain, Hailey and Megan have been influenced by the familial and social narrative that disability is a deficit, and that women are expected to continue with their responsibilities regardless of pain.

Making Sense of Pain Through Family Relationships

In Megan and Hailey’s narrative accounts, their relationships with their family shaped, and were shaped by, their pain experiences as children and teenagers. Stories that Megan retold about interactions with the scoliosis physician were storied through her mother’s reactions, recounting her mother’s anger and frustration at how Megan was treated. Similarly, Hailey described her mother’s anger towards Hailey’s pain being dismissed at her first psychiatric
consultation. The emotions and reactions of Hailey and Megan’s mothers were significant in affecting their pain experiences growing up. In their narrative accounts, their mothers advocated for their care, and Hailey and Megan described not having a voice in their own care.

As time went on, Megan’s pain experience shifted from stories of accessing health care with her mother to stories of university and learning responsibility for her own pain, learning to advocate for herself as an emerging adult woman living independently with chronic pain. As Megan became more independent, her mother became less present in her storied experiences of living with pain. Megan was expected to look after her younger sister at university, and these stories of responsibility created feelings of anxiety and stress, contributing to increased pain for Megan. Not being able to provide support to her sister when her pain was severe, Megan experienced guilt and stress for not meeting expectations set by herself and her mother.

Hailey’s narrative account made visible the ways her parents did not acknowledge her pain experience. Her stories of pain as a child were met with a lack of empathy, and Hailey stopped mentioning her pain to her parents, establishing her understanding of constant pain as a normal human experience. Over time, as Hailey grew into a teenager, her narratives shifted to experiencing pain dismissal from her parents for other reasons. Her parents attributed her chronic pain to her eating disorder, and they interpreted her limited ability to move as a lack of willingness to improve mentally. Additionally, her parents believed her migraines were solely an excuse not to attend school. Over time, these experiences contributed to Hailey understanding the stigma of fibromyalgia as “not a real disorder.” Physical touch became painful for Hailey in high school, creating tensions with her mother, which Hailey made sense of as her mother not understanding her pain. When Hailey had to quit skiing because of her health, her father displayed disappointment. Disappointment from both her parents related to her mental and
physical health influenced Hailey’s perception of herself, becoming a young person living with pain, and disappointing others.

**Stories of Being Silenced in Health Care**

In their narrative accounts, Megan and Hailey also experienced dismissal as they encountered health systems, and experienced being silenced in spaces of health care. From an early age, the scoliosis clinic became a significant place in Megan’s experiences of living with pain and how she became storied by others. From age 12 to 16, her encounters with the scoliosis clinic physician impacted her understanding of pain as something easily dismissed and not believed. For example, at the scoliosis clinic, she was repeatedly told that scoliosis does not cause pain, despite her ongoing pain experiences, leading to feelings of dismissal.

Megan’s experience of pain in teen hood bumped up against physician narratives about her pain, and her narrative account of this time in her life contrasts the clinic notes about her. In making sense of these experiences, she attributed her dismissal experiences to a lack of time the physician had to spend with her, who Megan thought had to see more than one hundred patients per day. Megan’s narrative account reveals experiences of being silenced as a patient in a larger institution, shaping who she was becoming as a young woman where her personal experience of pain was inconsistent with the physician’s explanations of pain. For example, over time, Megan began to conceal her pain in different settings, influencing health care interactions with male physicians.

Hailey also shared narratives in health care of not being seen as someone living with pain. Her experiences of dismissal are located in hospitals and doctor’s offices, places that shaped her future experiences as an emerging adult woman accessing care. Her pain was not only silenced by health providers, but she also became storied by health care providers as “not doing enough” or that her pain was a result of her eating disorder, depression, trauma experiences,
and/or anxiety. These interactions contributed to Hailey’s identity of herself as a woman living with pain as “not a fully functional human,” ascribing her pain as her own fault and affecting her self-esteem. Megan, through her narratives, resisted experiences of invalidation by health professionals, but felt challenges in doing so: “...it's hard to suddenly stand up to your ... doctor, for example, there’s such a cultural reverence to doctors that like, it'd be very intimidating, I think, to try to do that your first time.”

Women have historically been treated as biologically inferior to men, and treated in health systems constructed by the dominant gendered narratives of men (Connell, 2012; Levinson, 1976; Manandhar et al., 2018). Women who deviated from dominant health and gender norms were viewed as diseased individuals and labelled with “female personality problems”; women labelled as such were treated with psychotherapy or “tamed” by lobotomies or surgical removal of the clitoris or ovaries (Levinson, 1976). These dominant historical medical narratives (Nichols, 2000) were rooted in patriarchal norms, where male physicians were the gatekeepers of knowledge, and women were not given control over their own health (Zenner et al., 2012). Both Megan and Hailey reported dismissal of pain from male physicians and felt excluded from decision-making during medical encounters in teen hood. Their narrative accounts reveal feelings of dismissal related to being female, with narratives of being labelled as emotional or having their pain dismissed because of menstruation. Fears of not being believed resonated strongly across Megan and Hailey’s narrative accounts as patients in health care settings, as did having their pain dismissed, or attributed to psychiatric diagnoses.

The need to appear credible is a significant struggle for most individuals living with chronic pain, particularly among women with chronic pain (Toye et al., 2017; Werner & Malterud, 2003). Both Megan and Hailey experienced such tensions and struggles through their early and ongoing experiences of living with pain. Having medically unexplained pain can be
associated with shame, and individuals with chronic pain acknowledge there is a “right way” of being in pain to appear credible (Toye et al., 2017). Behaving the “right way” is a balance between appearing ill enough, but not too ill, to demonstrate the pain is “real” or legitimate (Toye et al., 2017). This balance, or “right way” of behaving to show pain, is so that the individual is perceived as a good person who is not to blame for their pain (Toye et al., 2017).

For Megan and Hailey, having a medically recognized diagnosis for their pain allowed them to make sense of who they were becoming as emerging adult women living with pain. As Hailey stated, having a diagnosis meant having a “word that describes all of it.” Having a medically acceptable cause for their pain meant it was no longer something purely psychological, thus considered “real” or legitimate, and this shaped acceptance of their pain as part of who they were becoming, encouraging them to move forward with their lives.

Experiencing dismissal for her eating disorder, fibromyalgia, gender, and sexual orientation, Hailey still finds it difficult to discuss her pain with care providers. Megan and Hailey prefer female physicians because of past experiences with male physicians where they felt dismissed for their pain. Hailey notes that, “… if I’m in the ER and realize that I’m, I’ve been assigned a male doctor like. It's just like please, please listen to me […].” Hailey’s experiences have led her to assume each patient-provider relationship begins with her being seen as not credible or trustworthy. These narratives of dismissal in health care became Hailey’s stories to live by, influencing her understanding of herself as an emerging adult woman whose pain is something to be dismissed or silenced. Emerging adult women have described a strong fear of being perceived as malingering (Barnes et al., 2018), and past experiences of dismissal have led Megan and Hailey to silence their own pain experiences in health care, with both now avoiding discussions on their pain unless initiated by the health care provider.

_Self-Doubt and Dismissal: The Consequences of Being Storied by Others_
Having experienced invalidation and dismissal of pain over time in spaces of family and health care, Hailey and Megan’s narrative accounts also show self-doubt and dismissal directed inward, or towards themselves. Over time, Hailey began to doubt herself and her pain experiences, wondering if it was real, part of her imagination, or psychogenic in nature as it had been storied by others in health care. Because pain is not visible to others, Megan and Hailey also share a common struggle to have their pain recognized by others, a struggle that is also internal. For example, Megan wishes her pain was more severe, and therefore more visible to herself, because of a tendency to invalidate her own pain. Perhaps struggling with self-compassion as a result of invalidation of their own pain, both Megan and Hailey describe difficulty taking pain medication or resting when needed, feeling they need to give themselves permission to do so.

Self-dismissal is not unique to Hailey and Megan. Dismissal and disbelief about chronic pain from friends, family, and health care providers is stigmatizing and can lead to shame, self-blame, and demoralization (Bernhofer et al., 2017; Carter et al., 2002; Carter et al., 2013; Werner & Malterud, 2003). For Megan and Hailey, their narrative accounts describe years of dismissal experienced through familial, cultural, and institutional narratives. These experiences of invalidation of pain from family and health care providers have shaped how Megan and Hailey story themselves, viewing their own pain experiences as less valid and silencing their pain experiences to avoid being dismissed by others.

**Pain Experiences Storied Through Relationships**

Adolescence, defined as ages 10 to 19, overlaps with emerging adulthood and is a critical formative period where individuals define and redefine themselves (Arnett, 2000; Klimstra, 2012). Identity formation is a key component of this developmental stage between childhood and adulthood, encompassing significant biological transitions and adoption of social roles that
represent a readiness to enter adulthood (Sawyer et al., 2018). For an adolescent living with chronic pain, reformulating their identity while trying to make sense of their chronic pain represents additional challenges as they enter emerging adulthood (Brown et al., 2021; Klimstra, 2012). Chronic pain worsened for both Megan and Hailey throughout adolescence and over time with stories of coming to understand their pain situated in places of school, health care, work, home, and in relationships with family, friends, and romantic relationships.

**Making Sense of Pain Through Intimacy with Others**

Megan and Hailey’s romantic relationships unfolded over time in narratives related to, and situated in places of, their pain. Megan was open about her pain from the beginning of her relationship with Justin, as was Hailey with Austin and Caleb. In Hailey’s narrative of disclosing her diagnosis, her internalization of decreased self-worth because of her diagnoses is evident when she asks Austin, “are you sure about this?” after revealing her health challenges, demonstrating how Hailey has been storied by others as damaged in some way. Over time in her relationship with Austin, Hailey storied Austin’s disrespect in relation to her pain as he treated her pain and limitations as something she should apologize for. Hailey’s personal narrative of denigrated self-worth is also evident when she imagines future narratives, questioning if she is deserving of a meaningful, healthy romantic relationship and whether someone would “want [her]” because of her health.

Hailey stories her relationship with Caleb by its effect on her pain during the COVID-19 pandemic. She experienced the early days of the COVID-19 pandemic with Caleb, a time which she described as the “COVID-19 lockdown.” During this time, she experienced some of her “absolute worst [pain] moments,” having been confined to Caleb’s room in his mother’s cluttered home. In Hailey’s narratives, Caleb stories her as unable to take care of herself, requiring constant care. Worsening pain occurred from being confined to bed during her
relationship with Caleb, sculpting Hailey’s understanding of her pain as something better managed on her own. Hailey now rejects this dependent narrative about her when imagining her future, and her identity as an emerging adult living with chronic pain has been shaped by her relationship with Caleb and how he storied her as fragile and dependent.

Additionally, both Hailey and Megan share narratives of ignoring their pain during sex. Dominant narratives about first sexual encounters led to Hailey and Megan believing that severe pain with first penetration was normal. Both Megan and Hailey continued to have sex despite pain, either from not knowing any differently, or perhaps stemming from a cultural belief that disability is something to be overcome, and chronic pain is something to be withstood without complaint (Logan & Curran, 2005; Wright, 2020). Beyond pain, self-guilt also exists in regard to physical intimacy for Hailey and Megan: Hailey experiences guilt for enjoying sex after having been sexually assaulted, and Megan experienced guilt for not being able to meet her partner’s needs when her sex drive was affected by Cymbalta, or when pain with sex was prohibitive. Guilt following sexual assault is not uncommon, and chronic pain patients of all ages experience guilt for not meeting the expectations of others (Lanthier et al., 2018; Toye et al., 2013).

Furthermore, physical or sexual abuse increases the risk of comorbid chronic pain and depression in emerging adults by approximately four times (Roberts et al., 2013).

During my time with Hailey and Megan, both women recalled experiences with trauma and assault. Interestingly, their experiences emerged in small pieces over time, and many were never fully told, but alluded to in a larger narrative. I often wondered about the minute trauma insights that both women provided to me, as well as silences that followed in between the telling

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23 Cymbalta (duloxetine) is a prescription medication used to treat chronic pain, depression, and anxiety. Among other side effects, decreased libido can occur with taking Cymbalta.
of such stories. At times, I felt that both Hailey and Megan were minimizing their experiences of trauma. However, given the stigma associated with each of sexual trauma and chronic pain (Lanthier et al., 2018; Monsivais, 2013), I can understand why these experiences were subdued in their narratives to avoid stigma. Alternatively, perhaps discussing their trauma would be retraumatizing, or, they lack the words to describe it. Still, I wondered why Megan and Hailey’s narratives of trauma have been minimized when trauma experiences can influence the severity and progression of chronic pain by reducing the pain threshold (Kumar & Lenert, 2017). Hailey believes her past sexual trauma influenced her progression of chronic pain, and sexual trauma and her pain seem inseparable in her narratives and artwork, defining her present and future experiences with sex as painful and sometimes re-traumatizing, further compounded by pain during sex because of her pain diagnoses.

The biopsychosocial experience of pain is multi-dimensional, with physiological, psychosocial, and social factors influencing the individual experience of pain (Force, 2019; Meints & Edwards, 2018). The narratives of Megan and Hailey reveal multiple traumas over the course of their teenage years whether social (e.g., pain dismissal from family or bullying at school), psychological (e.g., anxiety or Hailey’s self-harming and suicide attempts), institutional (e.g., pain dismissal and displacement in health care settings), or physical (e.g., experiences of sexual assault, Hailey’s eating disorder, or Megan’s car accident). Megan and Hailey described experiences of being “othered” at school for their physical limitations as well as bullying and sexual harassment while in France on school exchanges. Experiences of anxiety resonated across narrative accounts, and Megan’s car accident in university generated acute post-traumatic symptoms with panic attacks. Both emotional and physical traumas have been known to negatively influence chronic pain, especially in women, who are disproportionately affected by gender violence (Alexander et al., 1998; Finestone et al., 2000; Gómez-Pérez & López-Martínez,
Being storied as ‘Dis-abled’

Being storied as disabled is made sense of differently by Megan and Hailey, yet both identify as being disabled because of the things they cannot do rather than the things they can do in their lives. Megan’s story to live by as an emerging adult woman living with pain has unfolded over time, becoming inseparable from who she is. Today, Megan identifies strongly as being disabled. For her, stories of being “not normal” as a teen were replaced with stories of being disabled in her early twenties; becoming someone whose limitations began to shape her abilities. Over time, Megan gradually accepted and came to understand that she is someone living with a disability because of her limitations. Storying herself as disabled has gained significance in her stories to live by, describing that she would feel identity loss only if she no longer had pain. Furthermore, rather than describing herself as a “person with a disability,” Megan identifies herself as a “disabled person,” because, she says, “it’s who I am.”

Hailey makes sense of her disability as not being “a fully functional human,” having learned through not being treated “like a normal person” that she is disabled because of her limitations and accommodations needed at school and work. Hailey understands the cause of her pain as her “brain fucking [her] over,” yet attributes her resilience and ability to cope with adversity in part to her pain. In environments of health care, school, and work, however, both Hailey and Megan’s stories to live by—as disabled people—become muted, often at their own doing, to be able to adapt to and succeed in the world around them.

Different Landscapes: ‘World Traveling’

Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.
Sontag (1979) speaks to the metaphors with which the world of illness has been landscaped; in many ways, Megan and Hailey live in a world not designed for them, a world landscaped for the healthy. Sontag’s writing reminds me of Lugones’s (1987) metaphor of “world traveling.” Lugones wrote, “the shift from being one person to being a different person is what I call ‘travel’” (1987, p. 11). Megan and Hailey exist in multiple worlds and travel between these worlds, presenting different versions of themselves than that of their stories to live by. For Megan and Hailey, “world traveling” is not a choice or an option as much as it is a necessary part of daily life (Dewart et al., 2020; Lugones, 2003). Acting differently depending on context to avoid dismissal is Megan and Hailey’s response to the different landscapes encountered in their lives, matching Lugones’s (1987) description of “world” traveling (p. 12) as an experience of outsiders to the mainstream adjusting to the world around them (Dewart et al., 2020; Lugones, 2003).

Hailey and Megan’s ability to navigate multiple “worlds” (Lugones, 1987, p. 8) represents how future experiences become based on their past experiences of dismissal. While retaining their personal narratives of identifying as disabled, Hailey and Megan metaphorically travel to spaces where being able-bodied is the expected norm. Hailey and Megan’s understandings of their own identity as emerging adult women living with chronic pain are based on narratives of family, health care, and workplaces: “worlds” where they were, and are, not at ease. Living predominantly in these other worlds, Hailey and Megan have learned how to present a carefully crafted version of themselves, sometimes completely silencing their identity as disabled to avoid being seen differently or discriminated against. Both Hailey and Megan have learned how to behave to be seen as credible and competent, their understandings of which have evolved over time through experiences of being silenced and storied by others.
Resisting the Singular Stories of People Living With Chronic Pain

People who live with chronic pain appear to be storied in singular ways (Barnes et al., 2018; Brown et al., 2021; Samulowitz et al., 2018; Schäfer et al., 2016; Toye et al., 2020). For example, those with chronic pain are seen as exaggerating and weak, and storied by health care providers as difficult patients (Monsivais, 2013; Samulowitz et al., 2018). Such stories produce dominant narratives about people who live with chronic pain, and often result in people experiencing stigma in health systems (Ballweg et al., 2010; CPTF, 2019). Hailey and Megan’s narrative accounts show how they live alongside stories of people who experience chronic pain as being less competent and less worthy than others. Their narratives bump up against dominant societal and institutional narratives that chronic pain accompanies aging and visible disability, storying chronic pain in emerging adults as less valid, making it more difficult for emerging adults to establish credibility of pain without being perceived as malingering (Brown et al., 2021; Twiddy et al., 2017; Werner et al., 2004; Werner & Malterud, 2003; Werner et al., 2003). Megan and Hailey have storied themselves according to these dominant narratives, however, they have experienced tensions within their stories, in different spaces over time.

(Dis)ability: Says Who, and When?

Hailey’s narrative account is shaped by personal and cultural narratives that equate disability to being less deserving, and Megan’s narrative account reflects a societal narrative that individuals with disabilities are less competent and less productive. Megan also describes people with disabilities as being storied in society as a burden to others. Hailey and Megan story themselves, and are storied by others, as disabled emerging adults in places of work, health care, and school.

Narratives Hailey shared with me of being less worthy resonates with Toye et al.’s (2013) finding that emerging adults with chronic pain believe themselves to be irreparably damaged or
altered. Emerging adults with chronic pain are seen as less able to engage in normative activities, with increased dependence on parents and care providers (Brown et al., 2021; Mallen et al., 2005; Twiddy et al., 2017). Megan and Hailey’s narrative accounts show tensions between what they feel they are able to do, and how others story their (dis)abilities. For example, both Megan and Hailey reached independence from their respective families during their late teenage years, meeting milestones for emerging adulthood by developing their own identity, becoming independent in their decision-making, managing their own health, and becoming financially independent despite chronic pain (Arnett, 2000; Nelson & Barry, 2005). Their stories to live by contrast expected stories of emerging adults with chronic pain.

The narrative of being less worthy because of disability is also situated in Hailey’s work life, where she stories herself as less deserving of her job because of her physical limitations. Her stories of hopelessness are also situated in places of health care, describing herself as less deserving of therapy groups than an able-bodied person, since she feels there is “no hope for [her].” Looking forward, in Hailey’s narrative account, she reimagines her future with this story of being less competent when she rethinks nursing school, asking, “am I able to do that?” Hailey recognizes how she is storied by others for having multiple diagnoses, describing how she is viewed as unstable, and having learned that “it’s always something you need to omit [diagnoses] because otherwise […] the foundation on which they’re looking at you, is like unstable if they already know you have these other problems.”

Shaped by their experiences over time, Hailey and Megan’s reimagined future resonates with what is known about emerging adults living with chronic pain: they experience thwarted past, current, and future opportunities due to their pain, resulting in fewer employment and educational opportunities with future narratives of loss (Brown et al., 2021; Twiddy et al., 2017). Like women with chronic pain, emerging adults with chronic pain are often seen as weak or
exaggerating their pain (Brown et al., 2021; Twiddy et al., 2017). I often wondered if Megan worked through severe pain in graduate school because of fears that she would be seen as weak if she stopped to rest or asked for help in processing lab samples. She shared fears of losing both current and future opportunities if her limitations became evident. Megan voiced, “I’m supposed to like work through it, and live through it […] you’re not allowed to stop just because you have chronic pain.”

Both Hailey and Megan respond to such tensions by ignoring or concealing their pain, avoiding “giving a reason” for employers to discriminate against them, since past experiences – and the experiences of others – have illuminated this societal narrative that people with disabilities are viewed as less capable than others. While concealing their pain may avoid negative social repercussions, hiding their disability silences Hailey and Megan further in who they are becoming as women with chronic pain, perpetuating a lack of awareness around emerging adults with chronic pain, and shaping future experiences of dismissal.

**Dominant Narratives of Pain in the Context of Gender and Age**

Studies indicate that women are often assigned psychological rather than somatic causes for chronic pain, and pain that is not visible or measurable is less likely to be acknowledged by health care providers and more likely to be storied as medically unexplained (Samulowitz et al., 2018). Such dominant stories resonated with Megan and Hailey’s experiences of living with pain; their narratives revealed that pain was perceived as something “in their head” (Samulowitz et al., 2018). Hailey’s experiences of fibromyalgia as “not a real disorder” have influenced her stories to live by, explaining her pain as her “brain fucking [her] over,” and Megan’s experiences of being told scoliosis does not cause pain affected her understanding of what it means to live as an emerging adult woman with chronic pain.
While men with pain are portrayed as brave and stoic, women with chronic pain are perceived as complaining, emotional, hysterical, malingering, making the pain up, at fault for the pain, and not wanting to improve (Samulowitz et al., 2018). However, a higher proportion of women use active strategies for pain control like pain imagery and physical therapy techniques; furthermore, research on women’s experiences of pain emphasizes the substantial amount of work women living with pain put in to be taken seriously when accessing health care (Racine et al., 2014). Resonating across Hailey and Megan’s accounts is the narrative of being responsible for their pain and disability; over time, this has become part of their stories to live by. Hailey’s hospitalizations entail narratives where she was denied pain medication because she was not believed to be struggling and told her pain was either because she was “not moving enough,” or because she was experiencing depression. Retelling cultural and religious narratives where blame is attributed to the individual, Megan echoed beliefs she learned growing up, experiencing guilt around her disability as if she were responsible in some way for it.

The narrative of chronic pain as less valid in youth is also evident in Megan and Hailey’s narrative accounts. Culturally, youth is assumed to be a time of health, and emerging adults report feeling invalidated and dismissed because of their age, perceived as “too young” to experience a severe pain condition (Twiddy et al., 2017). Hailey’s experiences of dismissal in the hospital, on public transit, and with her peers mirror some of Megan’s narratives where dismissal of pain was experienced due to age: in school, and in health care encounters. This feeling of being invalidated because of a discrepancy between personal experiences and societal expectations of physical health leads emerging adults to feel isolated and a lack of acknowledgement for the severity of pain due to age (Twiddy et al., 2017).

Both Megan and Hailey challenge a dominant narrative that emerging adults with chronic pain are unable to maintain serious relationships, and are not sexually active (Stinson et al.,
Despite pain, Hailey and Megan still enjoy physical and emotional intimacy while working to address pain-related issues of sexual functioning. Over time, neither Megan nor Hailey settled for less in their relationships, as being storied as weak or less worthy may suggest. Through her narratives of relationships with Caleb and Austin, Hailey’s confidence increased and led to recognizing past relationships that were damaging to her self-worth. Hailey chose to end her relationship with Austin, who was not respectful of her pain, empowering Hailey and requiring courage. Megan states she would not have continued her relationship with Justin if he was not supportive and understanding of her pain, showing aspects of Hailey and Megan’s stories to live by as emerging adults with chronic pain that are worthy of love and respect.

**Stories to Live By**

Over time, the dominant narratives about women and emerging adults living with chronic pain altered how Megan and Hailey storied themselves, negotiating and renegotiating their identities, their *stories to live by*, as emerging adult women living with chronic pain. Having a story to live by allows an individual to make sense of themselves and sustains their identity in the face of adversity (Clandinin et al., 2000). Identity is multi-faceted, shifting over time, and for chronic pain patients, reconstructing their identity is both a challenge and a necessity to move forward alongside the pain (Toye et al., 2013). Megan and Hailey’s understanding of themselves and their stories to live by has been shaped by their experiences growing into adulthood through relationships and spaces of family, health care, romance, school, and work.

Shifting their stories to live by to someone with a disability was a gradual process over time, defined by their (dis)abilities in relation to others. Hailey’s story to live by as someone with fibromyalgia is a woman who has endured sexual trauma, struggles with mental health, and is dismissed for past trauma, multiple mental health diagnosis, her sexuality, and gender. Hailey views herself as being less worthy of love and support because of her diagnoses, having been
storied by others as dependent or broken, and describing herself as hopeless and unwanted: “…who would want me?” and, “…paired with the fibromyalgia and trauma it’s like, is there hope for me though.” Hailey’s story to live by as a child incorporated pain as a normal part of the human experience, as impacted by early family narratives of dismissal. As she experienced invalidation and disbelief through places of health care in teen hood, her stories to live by shifted to that of a woman with a disability, damaged by experiences of trauma and pain, and defined by multiple mental health disorders.

Megan’s story to live by since age 12 is that of someone living with chronic pain. She storied her younger self as “the girl with the brace,” and over time her understanding of herself shifted from being “not normal” to identifying as disabled. As time passed, believing her scoliosis would spontaneously resolve as a child became replaced with hope that surgery would cure her pain. Stories of being silenced at the scoliosis clinic and by her mother evolved into stories of being silenced in society, shaping a need to conceal aspects of her identity, linked to social context. Among the disability community, Megan, in the present time stories herself as “not disabled enough” to deserve certain accommodations or have the right to complain. Still, facing adversity in living with disability has become part of her story to live by and she attributes her insight, maturity, and empathy to living with chronic pain.

Part of Megan and Hailey’s stories to live by have also been created through resisting dominant narratives about them, becoming women who defy expectations set for them by others. Their narratives each portray a woman who seeks out challenge and succeeds in meeting their goals regardless of adversity faced along the way. As part of Hailey’s stories to live by, she describes herself as someone who enjoys being challenged, for example, by persevering through pain and illness on an intensive, multi-day canoe trip. Hailey is a talented artist now maintaining a full-time course load in university, living independently and conveying her experiences of pain
through art. Megan completed a master’s degree in a new city amid a global pandemic, with aspirations for medical school, and currently lives with her partner of eight years, supporting his endeavors as well as her own. Neither Hailey nor Megan’s narratives indicate they are a burden on those around them, and both represent themselves as independent and self-reliant in their narratives of living with pain.

Their stories to live by as emerging adult women living with chronic pain are subtle stories of strength, perseverance, and unique abilities that have resulted from living with it. Megan and Hailey’s achievements indicate ways they have resisted dominant narratives about them, yet aspects of their stories to live by demonstrate how societal narratives of disability and women’s pain have also become personal narratives.

Conclusion

Pain is a perception as well as a sensation, thus it is important to consider how the dimension of sociality influences Megan and Hailey’s experiences of pain (Galvez-Sanchez et al., 2020). Using the three-dimensional narrative inquiry space, inquiring into the commonplaces of time, sociality, and place revealed uncertainty, tensions, and complexity in the narrative threads that resonated across Megan and Hailey’s narrative accounts. Being silenced, invisible, and locating themselves within the pain was a resonant thread where Megan and Hailey made sense of their pain through experiences of dismissal in family relationships and health care encounters. Over time, they storied their pain experiences through relationships of intimacy and coming to identify as (dis)abled while muting this identity to adapt to the world around them. How Megan and Hailey have been storied as (dis)abled has informed much of their identity, yet both defy singular stories of people living with chronic pain by empowering themselves in ways that include living independently, having serious relationships, enjoying physical intimacy, maintaining employment, and succeeding in post-secondary education.
Living with chronic pain has required fluid ways of living for Megan and Hailey in worlds where guilt, dismissal, and trauma influence their experiences of health care, work, family, and romantic relationships. Their stories to live by as emerging adult women with chronic pain differ, yet they both identify as disabled while adapting how they present themselves, as they travel to metaphorical “worlds” and landscapes not designed for them. Furthermore, Megan and Hailey’s narratives reveal tensions that bump up against the dominant social, cultural, familial, and institutional disability narratives that indicate emerging adult women with chronic pain experience invalidation shaped by hegemonic patriarchy, ageism, and ableism.
Chapter 7: Reflective Turns

One voice can be enough to spark institutional change. (Bullock, 2021)

The purpose of qualitative research is to generate knowledge about a particular phenomenon from the perspective of those who have experienced it, and it is useful in understanding topics that have been largely unexplored (Holloway & Wheeler, 2010). In narrative inquiry, knowledge is generated through stories shared by participants in addition to stories shared by, and with, the researcher, representing a co-creation of knowledge from experiences (Clandinin, 2016).

As the relational space between myself, Megan, and Hailey evolved over time, we imagined future ways in which the lives of emerging adult women with chronic pain could be improved, drawing upon the concept of continuity in the three-dimensional inquiry space. In this concluding chapter, I return to my justifications for this inquiry and discuss the personal, social, and practical significance of this narrative inquiry. I also reflect on my own experiences conducting this narrative inquiry: having challenged my own personal and institutional narratives while conducting research virtually during a pandemic, pivoting from sexual health nursing to chronic pain research, and learning to embrace the concepts of mutual vulnerability, “world travel”, and wakefulness as someone with lived experience of chronic pain.

Personal Significance

Individually, we lead storied lives; according to Connelly and Clandinin (2006), our stories represent “a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful” (p. 479). For me, this inquiry has been significant in my own stories to live by (Clandinin & Connelly, 2000) – who I
am as a registered nurse and woman living with chronic pain, and who I am becoming as a health researcher and advanced practice nurse.

In sharing my own stories of living with chronic pain, there has been a sense of unburdening and freedom in allowing my previously hidden chronic pain to become visible. In becoming a narrative inquirer, I have also learned to listen to the silences in conversation: silences that suggest silenced voices and stories untold. Through the process of engaging in this narrative inquiry, mindfulness has become wakefulness and vice versa, for my daily mindfulness meditation practice has expanded to moments outside of the time I set aside to practice meditation. This inquiry has helped me to be more attentive to the needs of others and validated some of my own experiences that I share with Megan and Hailey. I have learned that both narrative inquiry and nursing practice are a practice of paying attention, and symbiotic to my mindfulness practice.

My practice as a registered nurse has also been shaped by this inquiry. I have begun to challenge some of the boundaries created by institutional narratives that exist between the patient and healthcare provider, finding ways to inquire meaningfully alongside patients in my professional role. My friends have noticed a shift in my relational way of being, too. I called my oldest friend late one evening in the middle of December, and she described a difference in how I attend to her words. I realized that this narrative inquiry has shifted the way I attend to relational ethics outside of my graduate work, helping me to “understand more deeply the ways that moving slowly allow the possibility of living and listening” (Clandinin et al., 2018, p. 94). Subsequently, my desire to continue challenging the dominant social, cultural, and institutional narratives in each world I inhabit has only been fueled further.

**Practical Significance**
Health and nursing practices are dynamic, defined by a continual interaction between human behavior and thoughts that bump up against tensions in the personal, social, and institutional spaces we inhabit (Wang & Geale, 2015). Stories are a powerful tool to gain a deeper understanding of experiences, and patient-centered care can only occur when the individual experience of care is recognized and understood contextually.

**Significance to Nursing Practice**

Hailey, Megan, and I determined several recommendations based on their experiences. Adequate communication and education from the provider were crucial aspects of health care that when absent, perpetuated negative perspectives of health care, and resulted in inferior care outcomes for Megan and Hailey. Emerging adult women may not feel comfortable bringing up their pain concerns with their primary health care provider due to stigma, previous experiences of dismissal, and power dynamics in the patient-provider relationship. Therefore, it is important that providers regularly initiate conversations around pain management when caring for emerging adult women that experience chronic pain and incorporate ways to practice that are de-stigmatizing and show engagement with the patient’s concerns. Emerging adults may not disclose their chronic pain when asked about medical history, thus regular screening for chronic pain may be necessary. Comorbid diagnoses should be addressed concurrently with chronic pain since pain, mental health, and trauma are interconnected. Narrative practices have utility beyond narrative inquiry, and narrative medicine helps deepen the understanding of patient experiences through listening to patient stories with *narrative competence*, defined as “the capacity to recognize, absorb, metabolize, interpret, and be moved by stories of illness” (Charon, 2007, p. 1265).

In addition to communication and education, Megan and Hailey stress the importance of validation and empathy in health care. Consequences of feeling dismissed led to their pain being
largely unaddressed. Decreased trust in the health care system arose; difficulty practicing self-compassion and navigating social and occupational roles resulted. Thus, health care providers should emphasize validating the severity and chronicity of pain in patients of all ages, especially when interacting with populations that experience frequent invalidation of their pain. This can be done by acknowledging the impact that chronic pain has had on the patient’s life and verbalizing recognition of chronic pain as a legitimate condition (Health Canada, 2021; Pain Society of Alberta, 2019).

Emerging adults may be unaware of social supports available to them and may lack expertise navigating the health care system; assistance with accessing supports and health systems may be helpful when caring for emerging adults with chronic pain. Social supports can also include assistance in finding supportive employment since this narrative inquiry revealed significant discrimination in the workplace related to disability.

Because Hailey and Megan’s pain is invisible, recognition of pain by others as well as themselves is often elusive. For teens navigating chronic pain, keeping a pain journal may assist in self-validation and acceptance of pain, encouraging self-management by increasing recognition and understanding of their own pain. Having patients visually represent their pain may also facilitate greater understanding and belief of pain among their family members. Findings from this study indicate family relationships have a significant impact on individual pain beliefs during adolescence and emerging adulthood; in this study, those family relationships were primarily mother-daughter relationships. Hence, nurses can improve patient care by fostering the family’s understanding of their child’s pain. For example, nurses can practice family-centered care by facilitating open communication between family members and the patient (Coyne et al., 2018). Family nursing theories emphasize the importance of collaborative family relationships in illness management (Kaakin et al., 2018; Kokorelias et al., 2019;
Leahey & Wright, 2016; Lyons & Lee, 2018), and a referral to family counselling may be beneficial. Effective family functioning enhances patient and family quality of life, and nurses can assist to improve holistic care outcomes within the context of familial relationships (Lyons & Lee, 2018).

Nurses are well-positioned to provide appropriate sexuality education; however, many nurses fail to engage in compassionate, meaningful conversations about sexual health with patients (Fennell & Grant, 2019). Addressing pain-related issues with sexual relationships has been identified as a priority in emerging adults living with chronic pain (Brown et al., 2021; Stinson et al., 2013). Where appropriate, health care providers should regularly screen for relationship concerns and interference in sexual functioning with chronic pain patients so that interventions can be implemented.

The invisibility of pain means that it is often absent from conversations and not recognized as an issue in health care (Hirsch, 2018). Nurses can further improve the experience of emerging adults living with chronic pain by normalizing chronic pain in all ages. Nurses are well-positioned to be agents of change (CNA, 2019) and should advocate for chronic pain patients at high risk of dismissal in interactions with physicians, other health care staff, and patient family.

**Significance to Health Education, Research, and Policy**

Given the invalidation of pain in emerging adults and a lack of tailored services towards this demographic, nursing interventions tailored to emerging adults – and women – should be offered. In addition, availability of interdisciplinary services outside of work and school, age-specific support groups, and discussions around topics of importance to this age group (e.g., identity, self-management, body image, side effects of medications, pain and sleep, navigating relationships and sexuality) should be considered when developing models of care.
Financial barriers are likely when emerging adults are attending school or living independently. Hailey and Megan reported massage therapy to be one of their most effective pain management strategies, however massage therapy is not publicly funded in Alberta. Mind-body therapies, first widely promoted in Western medicine by Jon Kabat-Zinn (Kabat-Zinn & Hanh, 2009), include massage and have proven beneficial in treating chronic pain disorders (Elibol & Cavlak, 2019; Lee et al., 2014). At times, Hailey also struggled to afford her medication. Many emerging adults may not have private health insurance, thus subsided or publicly funded options of effective pain management strategies should be explored to address the chronic pain trajectory and burden of disability in society (Stinson, 2013).

In nursing education, chronic pain remains a topic rarely discussed, particularly in relation to stigma and marginalization. Early intervention with chronic pain can alter the chronic pain trajectory, yet many emerging adult women do not seek care for their pain. With such an impact on individuals and our health care system, the complexity of chronic pain should be incorporated into nursing education, and the myth that only older individuals experience chronic pain should be addressed to avoid future experiences of dismissal and stigma in young chronic pain patients.

Little qualitative research exists on the specific impact of chronic pain in emerging adults. Since much of the literature on chronic pain focused on middle-aged to older individuals, more research on chronic pain is needed on emerging adults and emerging adult women, who likely have unique pain experiences (Brown et al., 2021). To my knowledge, this is the first study to use Clandinin and Connelly’s (2000) form of narrative inquiry to explore chronic pain, and, to qualitatively examine the experiences of women aged 18 to 29 living with chronic pain rather than specific disorder. Canadian pain research lacks emphasis on a holistic understanding of the pain experience (CPTF, 2019) and emerging adult women with chronic pain are a
particularly understudied population (Hirsch, 2018). Additionally, individuals with chronic pain may be more vulnerable to challenges faced during emerging adulthood (Twiddy et al., 2017).

More research is needed to understand the chronic pain experiences of emerging adult women. Longitudinal studies could address existing gaps in knowledge on etiology, incidence, treatment effects, and outcomes of chronic pain in emerging adults (Brown et al., 2021), as well as studies that examine how tailored interventions can improve quality of life when designed in the context of age and gender. Given that the last Canadian prevalence study that provides chronic pain estimates for emerging adult women was published in 2011 (Schopflocher et al., 2011), current population prevalence studies are necessary to evaluate the present burden of chronic pain in emerging adults. In general, a greater focus on the understanding of unique pain experiences during emerging adulthood is warranted to improve treatment options and long-term outcomes for this demographic (Brown et al., 2021).

Social Significance

When I began this inquiry, one social justification to my work was to generate awareness and understanding of the experiences of emerging adult women living with chronic pain; that is, to help outsiders “world travel” into these worlds (Lugones, 1987, p. 12). In simpler terms, I hope that others can travel into Megan and Hailey’s worlds, and by doing so, begin to understand emerging adult women who live with chronic pain. In making the stories of Megan and Hailey visible, awareness of this population can be increased, even in small ways. What this narrative inquiry demonstrates is that the knowledge to be heard, validated, and trusted is important to people in the midst of living with chronic pain. I hope that Megan and Hailey have experienced some sense of unburdening in sharing their stories with me, knowing it may encourage other women to challenge dominant narratives that silence us.
Each time I explain my thesis to a patient, colleague, or family member, I am offered a story of a young woman who experienced dismissal of pain and an arduous diagnostic journey through health care. This story may be about themselves, their daughter, their friend, or someone else they know. Stories spark stories, and if the awareness of emerging adult women with chronic pain is increased, the dominant narratives around this population that perpetuate marginalization – and women with chronic pain – may begin to evolve.

By learning about these experiences, the social and theoretical conversations around chronic pain can begin to shift, altering the discourse which has shaped the experiences of Megan and Hailey. Furthermore, making the stories of this population known can begin to improve the social, cultural, familial, and institutional experiences (Clandinin & Rosiek, 2007; Green, 2013) of other emerging adult women living with chronic pain. In storying emerging adult women with chronic pain differently - and storying those with chronic pain and invisible disabilities differently - social narratives may begin to shift to highlight the resilience, determination, and unique strengths that individuals living with chronic pain possess (Clandinin, 2016; Finlay, 2020; Souza, 2017; Tan, 2019).

I hope that the dismissive comments Hailey, Megan, myself, and other emerging adult women receive in our daily lives will shift to comments that exude empathy, respect, and a willingness to understand. The discipline of nursing is well-positioned to change the harmful social and cultural narratives made evident in this narrative inquiry. If these narratives are shifted, emerging adult women with chronic pain may have a better diagnostic journey, improved family relationships, and the self-esteem and social support to seek healthy, meaningful relationships while pursuing personal and career development goals. Social change may be small to begin with, but more often than not, it begins with a story (Brass, 2018; Clandinin et al., 2018; Kubota, 2017; Lessard, 2014; Steeves, 2006).
Final Reflections

Please begin to learn and as I say, come to live with an understanding that there is knowledge outside the way you live.

-Dustin Brass

As Brass (2018) alludes to, placing ourselves outside of our “worlds” in which we are at ease allows for profound learning. I experienced both challenges and profound reflexivity in this narrative inquiry work, much of which has influenced who I am as a narrative inquirer, registered nurse, and perhaps as a future doctoral student. Challenging my own narratives around professional boundaries and academic research complemented over 100 pages of reflective field journal notes and autobiographical writing I wrote since beginning data generation in June 2021. In pivoting my nursing practice as a sexual health nurse to a qualitative chronic pain researcher, the concepts of mutual vulnerability, “world traveling,” wakefulness, and merging identities became frequent ruminations as I returned again and again to the ontological commitment of narrative inquiry and its commonplaces of time, sociality, and place.

One challenge was the inability to attend in-person events or places significant to the participants. Due to COVID-19 public health recommendation, the entirety of our inquiry space was created virtually via Zoom. Rather than meeting in a room on-campus (where they would enter my world) or visiting them in their home (where I would be entering their space), we created a virtual inquiry space together. This virtual Zoom space allowed for us to see into each other’s world through glimpses into each other’s homes. The balance of power somehow felt more equal this way, despite not being able to physically come alongside Megan and Hailey “in the midst” (Clandinin & Caine, 2013, p. 169) of their lives. Still, I wonder how I might have come to know Hailey and Megan differently if we had not been restricted to Zoom meetings.

Pivoting From Sexual Health to Chronic Pain: Mutual Vulnerability and Wakefulness
I intentionally chose to pivot from years of nursing practice in sexual and reproductive health to focus on chronic pain in my master’s degree. I had much to learn about the evolving landscape of chronic pain beyond my personal experience, particularly in the context of narrative inquiry research. Undergraduate nursing education and years of nursing practice taught me to uphold strong boundaries between my personal and professional lives, and I struggled to embrace the concept of mutual vulnerability. hooks (2010) evoked this hesitance to share personal stories, and alludes to the importance of recognizing stories in academia:

I had been trained to believe that anyone who relied on a personal story as evidence upholding or affirming an idea could never really be a scholar and/or an intellectual, according to dominator thinking via schools or higher learning. (p. 49)

Disclosing my own lived experience with chronic pain felt purely unprofessional until I understood that our own stories are an integral component of narrative inquiry (Clandinin & Caine, 2013). I first divulged my diagnoses and personal connection to my work when encouraged to do so in my research proposal. Then, I became more open about my chronic pain with friends, family, and with Megan and Hailey. I had chosen to pursue an inquiry with personal relevance, and so placing myself alongside my participants led to deep reflection and self-exploration. I contemplated how much of myself I was willing to share with Hailey and Megan, and place in the final texts.

Concurrently, I took a two-week intensive graduate course on narrative inquiry through the University of Alberta. The course was nothing like I expected. Cultivating deep reflection, creativity, and a space to explore my own merging identities encouraged me to practice wakefulness in the relational ethics of my narrative inquiry (Clandinin et al., 2018). Wakefulness, as introduced by Greene (1977), refers to being “wide-awake”, attentive, and curious to the layers of experience made visible through inquiring into others’ and our own lives. For me, being wakeful opened doors to practicing mutual vulnerability, fostering a deeper commitment to the
inquiry. Without this reflexivity and mutual vulnerability, I would not have been shaped by this inquiry, nor it by me.

**“World Traveling” as Researcher and Patient**

As a 29-year-old woman living with chronic pain, I came to the inquiry familiar with aspects of Hailey and Megan’s “worlds.” However, as my 30th birthday looms at the time of writing this thesis, I am on the brink of what follows emerging adulthood. With this knowledge, I wonder how I had situated myself in the inquiry. In recognizing the multiplicity of worlds and complexity of experience (Dewart et al., 2020; Lugones, 1987), I entered the inquiry recognizing that my experiences as an emerging adult women with chronic pain may not be the same as Hailey and Megan’s, and I became diligent in practising wakefulness.

One day in late autumn while waiting for the snow to arrive, I was reflecting on assigned readings for my monthly narrative inquiry discussion group when I experienced overwhelming emotions. I was contemplating again my reasons for doing this work – my personal, practical, and professional justifications. I felt the responsibility in retelling Megan and Hailey’s stories. I felt passionate about doing this work, but also immense pressure.

The thoughts I had reminded me to return to the question of who I am in this inquiry, to practice wakefulness. How was I positioning myself as the researcher, someone with lived experience of chronic pain, and a registered nurse? A strong personal and social justification was to improve the experiences of others with chronic pain navigating the world, by making visible the experiences of Megan and Hailey. There were narratives that could further the dominant narrative about women with pain as malingering; I wondered, “Should I exclude those narratives?”

By wanting to increase awareness of the challenges that emerging adult women with chronic pain face, it would have been easy to exaggerate Megan and Hailey’s negative
experiences accessing health care while making less visible their positive experiences. I questioned for some time, am I offering an accurate description of experience? Recalling Lugones’ (1987) metaphor of “world traveling”, I kept close the narrative inquiry touchstone of “coming alongside in the midst” (Clandinin, 2013, p. 34) and situated myself in being attentive to my own worlds, the worlds of each participant, and the worlds that were co-composed by myself and the participants (Clandinin & Caine, 2013; Dewart et al., 2020). Stories are a retelling of remembered experiences, a telling which shifts over time, place, and social context (Clandinin, 2016). Therefore, memories are not exact replications of past experiences: stories are always told in the present time, place, and social context, and narrative retellings of past events are only as accurate as the participant and researcher’s recollections (Clandinin, 2016). However, it is the intimate understanding of storied experience over time and in context that is significant to narrative inquiry (Clandinin, 2016; Clandinin & Caine, 2013).

**Conclusion**

Stories are a way that humans build and create meaning (Clandinin, 2006). As Wang and Geale (2015) wrote, “narrative inquiry amplifies voices that may have otherwise remained silent” (p. 195). Pain is an experience influenced by biological, psychological, and social domains (Gatchel et al., 2007). Women are disproportionately affected by chronic pain, yet women’s pain is frequently discounted or underestimated by medical professionals (Ballweg et al., 2010; Malin & Littlejohn, 2012). Because of these biases, women with chronic pain struggle for credibility and must display significant determination to receive investigation and treatment, in addition to coping with chronic pain (Werner et al., 2004; Werner et al., 2003). Consequently, chronic pain conditions in women are more likely to go undiagnosed and remain inadequately controlled (Ballweg et al., 2010). Emerging adult women are at higher risk in primary care for insufficient pain management (Green & Hart-Johnson, 2010), and face unique
challenges navigating chronic illness, dating, body image, college, careers, establishing independence from family, and bearing children at an age where youth is equated to being healthy (Hirsch, 2018; Stinson et al., 2013).

Past experiences of navigating daily life with chronic pain can reveal the social narratives that exist about those living with chronic pain, as well as the individual narratives that shape present and future interactions. Using Clandinin and Connelly’s (2000) form of narrative inquiry, in this thesis I explored how living with chronic pain shapes the identity of emerging adult women aged 18 to 29. Narrative identities of two emerging adult women, Megan and Hailey, were made visible by using Clandinin and Connelly’s (2000) *three-dimensional narrative inquiry space* to understand the influences of interaction, continuity, and situation in storied experiences of living with chronic pain.

In chapter 4, Hailey’s narrative account revealed a complex intersection between chronic pain, trauma, and mental health. Her stories of teen hood were marked by hospitalizations and panic attacks, the pain worsening alongside her mental health until an official fibromyalgia diagnosis was received. Layered dismissal was narrated in social and physical spaces of health care, family, school, and work; experiences of being silenced in social, familial, and institutional settings contributed to decreased self-esteem, acceptance, and self-compassion. Personal narratives about disability and decreased self-worth led to significant personal growth through romantic relationships which Hailey described as toxic, evolving into Hailey’s rejection of many dominant narratives about women with chronic pain.

In chapter 5, having been diagnosed at age 12, Megan’s narrative account of living with pain began with a scoliosis diagnosis given in the emergency department. Experiences of being silenced at the pediatric scoliosis clinic overlapped with experiences of dismissal from her mother. These experiences contributed to Megan’s understanding of what it means to live with
chronic pain, perpetuating a familial and cultural narrative that women are expected to work through pain. Megan’s pain progressed throughout her education as her beliefs about what it means to be disabled evolved and gradually shifted to a place of acceptance, regardless of how others may perceive her.

However, both Megan and Hailey chose to conceal their pain in environments where revealing their disability could create negative social, emotional, and physical consequences. In chapter 6, narrative threads that resonated across Megan and Hailey’s narrative accounts reveal stories of being silenced, making sense of their pain through relationships with others, and coming to identifying as disabled. We learn how Megan and Hailey have been storied in health care as exaggerating, malingering, or their pain storied as entirely psychological. Family narratives of pain dismissal centered around their respective mothers, relationships that created feelings of invalidation and influenced personal narratives about disability and self-worth. Megan and Hailey further experienced invalidation as dismissal and a lack of acknowledgement for their pain due to age in places of school, health care, and work. These experiences of how emerging adult women with pain are assigned a singular story contributed to Megan and Hailey’s awareness and resistance of dominant narratives about them, shaping their identity and stories to live by as empowered, self-determined women achieving beyond how emerging adults and those with disabilities have been storied.

Given that chronic pain worsens with age (Syx et al., 2017) and adults regulate their emotions differently as they age (Barnes et al., 2018), understanding the experiences of women with chronic pain in emerging adulthood is crucial to early and successful management of chronic pain. Recognition of the individual pain experience supports improved diagnosis, and research confirms the need for care models tailored to individual needs (Souza et al., 2017). This narrative inquiry provides insight into the experiences and needs of a demographic that
has numerous decades of life remaining. Furthermore, this study contributes to increasing awareness on the experiences of emerging adult women, offering a greater understanding of the sociocultural context of health care encounters with this demographic. Findings from this inquiry, combined with existing gaps in the literature, signifies a need for the stories of emerging adult women with chronic pain to be attended to.

Lugones (1987) metaphor of “world traveling” can provide another rationale for my work by making visible the experiences of two emerging adult woman living with chronic pain whose worlds are often overlooked or made invisible (Dewart et al., 2020; Hirsch, 2018). By naming the spaces in which this population experiences marginalization, inequity can be uncovered. In this inquiry, “worlds” formed through discrimination and dismissal have been made visible and there is potential for emancipation through increasing awareness of Hailey and Megan’s worlds. By beginning with recognition, we can begin to shift the predominant medical and societal discourse on emerging adult women with chronic pain to one that accurately reflects the experiences of an underserviced demographic where little has been formally established.
Epilogue: Moving Forward

As I transition from my time with Hailey and Megan to what awaits me upon completion of my master’s degree, I continue to reflect on how this inquiry has shaped me. Having remained semi-sheltered from the COVID-19 pandemic as a Master of Nursing student and work-from-home registered nurse, I have spent much of the last 24 months in a reflective cocoon in the suburbia home that I share with my husband. My time spent walking alongside Hailey and Megan’s lives may have been fleeting, but the time spent together has shaped me in ways that will likely remain intangible for years.

Perhaps Hailey and Megan have shaped me more than I have attended to their stories. I find myself viewing the world differently. At a recent ophthalmologist appointment, I viewed the process of shuttling through rooms - seeing different technicians, and finally the physician - from a different perspective, and was perplexed by the lack of accessibility. I drove there, so if I could not walk far, I would have had to pay for on-site parking rather than park a block away for free and walk. Being disabled can make it difficult to earn a sufficient living, so how would paying for parking at my numerous appointments affect me? I may have had to take unpaid time off work to attend this appointment.

Once I entered the building, the waiting room chairs were uncomfortable. The testing room was dark and cluttered, and I had to navigate many obstacles. The chinrest for the diagnostic machines were awkward; I had to bend myself to them, jutting my chin forward, scrunching my shoulders and hyperextending my back long enough to exacerbate my pain. There was a long line up for the washroom, where I stood for fifteen minutes with no chairs in sight. I doubt these things would have registered with me before; I would have thought little about the lack of ergonomics of the testing machine, adapting without a second thought. As I left this time,
I wondered why I didn’t ask them to raise the chinrest. It seems I often forget I am not able-bodied, for I try so hard to blend into a world not designed for us.

When my thesis was almost written, I watched a documentary on a 14-year-old boy’s experience with chronic pain, *Bend or Break*. After years of misdiagnoses and having the pain dismissed for psychiatric reasons, he was eventually diagnosed with Ehlers-Danlos syndrome. I turned to my husband after the film ended and said, “I would say thank you for loving me even though I have Ehlers-Danlos syndrome, but that would mean I am less deserving of love because of my condition. So, instead, thank you for loving me.” He sweetly responded, “If anything, you are more deserving of love.”

Yes, disability is a spectrum, and pain is invisible, but the world is not designed for us. We adapt to the world instead, and there are costs. I have learned this from Hailey and Megan, and I see the world a little bit differently now. I see it from the perspective of someone with a disability doing their best to navigate an environment that is not designed for them. I see it from the perspective of someone that lives in a world that does not see them. The knowledge Megan and Hailey shared will stay with me long past the time we remain in contact, and I wonder in what small ways I have shaped their lives, too. I hope that they feel seen.
Appendix A: Study Recruitment Postcard

**ARE YOU AGED 18 TO 29?**

If you have persistent pain, this study may be for you.

**We are recruiting participants for**

**YOUNG ADULT WOMEN WITH CHRONIC PAIN:**

**A NARRATIVE INQUIRY**

You may be eligible if you are:
- a woman
- 18 to 29 years old
- have been living with persistent (chronic), non-cancer pain for more than 3 months

Ethics ID: REB21-05401
This study has been approved by the University of Calgary Conjoint Faculties Research Ethics Board

**WHAT WILL YOU DO?**

- complete 3 to 4 in-depth interviews on living with chronic pain
- talk about your experiences living with chronic pain and how it affects you
- discuss your experiences further with follow-up communication

The purpose of this study is to explore the experiences, challenges, and needs of young adult women living with chronic pain. This study also aims to understand how living with chronic pain shapes the identity of young adult women.

For more information contact Jenise Finlay at jenise.finlay@ucalgary.ca or 403-996-0901

Ethics ID: REB21-05401
This study has been approved by the University of Calgary Conjoint Faculties Research Ethics Board
Appendix B: Conversational Interview Questions

1. Tell me a little about yourself (background)
   a. Where did you grow up?
   b. What was your childhood like?
   c. How would you describe yourself now?

2. Getting to know the Participant
   a. Tell me about your life living with chronic pain. Can you tell me how long you have had chronic pain and what it has been like for you?
   b. Tell me about when the pain started, or when you didn’t have physical symptoms, or before it was diagnosed and became more significant in your life.

3. Experience of living with a chronic pain condition
   a. What has living with a chronic pain condition been like for you?
   b. What are the main ways living with chronic pain is impacted you? (Twiddy et al., 2017)
   c. How do you understand your pain? (Twiddy et al., 2017)
   d. Can you tell me about how chronic pain affects the other aspects of your life?

4. Learning to manage the pain
   a. What has or would help you learn to cope with your pain condition?
   b. How have you learned about your chronic pain and how to manage it?
   c. Can you tell me about any difficulties you have had learning more about your chronic pain and how to manage it?
   d. If you had to tell someone else about how to manage or cope with their chronic pain what would you tell them?
e. What do you need to know about your chronic pain in general to feel comfortable managing it independently (or on your own)?

5. Experience of medical encounters and getting diagnosed with chronic pain
   a. How have medical encounters affected your experiences living with chronic pain?
   b. What does a diagnosis mean to you?
   c. Can you tell me about any difficulties you have had accessing services to help you deal with the impact of chronic pain on your daily life?
   d. Can you tell me what it was like when you moved from a pediatric to an adult medical center for your chronic pain care?
   e. What services would you like to have available to help you manage your pain?

6. Experience with treatments
   a. Of the treatments offered for chronic pain—including medication, physical, or psychological therapies—are there some treatments that work best or you are more likely to try than others?
   b. Have you had any trouble getting medicines or other treatments such as physical and psychological therapies?
   c. What information do you need to have about medicines and other treatments such as physical and psychological therapies to feel comfortable managing your pain independently (or on your own)?

7. Experience of disclosing pain and illness
   a. Tell me about disclosing your illness/pain to those in your life. How do you decide who to disclose to, and when?
b. What is it like to talk about your chronic pain to your doctors and nurses? Family? Friends? Teachers? Employers?

c. Tell me about some of your experiences disclosing.

d. How do you explain chronic pain to friends and family?

8. Experience of living with chronic pain on relationships

a. Sub Topics: What impact does living with chronic pain have on your relationships such as work, family, friends, dating, and romantic relationships?

b. How do your family/friends help to support you?

c. Retaining employment: how does living with chronic pain affect your ability to make a living? To retain meaningful work? What aspects of living with CP affect your employment?

9. Experience of gender on living with chronic pain

a. Tell me about specific issues that impact you as a woman living with chronic pain.

10. Experience of age on living with chronic pain

a. Tell me about how your experiences living with pain may be different than those of someone older who is living with chronic pain.

11. Influence of chronic pain on identity

a. How has living with a chronic pain condition changed how you see yourself?

b. Has living with a chronic pain condition changed how you see your future?

(Twiddy et al., 2017)

c. How do you think chronic pain will affect you in the future?

d. What kind of services would be helpful for you to deal with your future concerns about your chronic pain?
Appendix C: Consent Form

UNIVERSITY OF CALGARY

CONSENT TO PARTICIPATE IN RESEARCH

TITLE: Young Adult Women with Chronic Pain: A Narrative Inquiry

SPONSOR: University of Calgary

INVESTIGATORS: Jenise Finlay (Master of Nursing student), Aniela dela Cruz (academic supervisor)
Phone: 1-403-210-7484

INTRODUCTION

Jenise Finlay and associates from the Faculty of Nursing at the University of Calgary are conducting a research study.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

You were identified as a possible participant in this study because you have experience living with chronic pain. Your participation in this research study is voluntary.

WHY IS THIS STUDY BEING DONE?
Many chronic pain syndromes affect more women than men. Young adult women face unique challenges navigating chronic illness and often report feeling dismissed during health care encounters. Few studies look at the experiences of chronic pain only in women under 30.

The purpose of this research study is to explore the experiences of women aged 18 to 29 living with chronic pain. The study aims to increase awareness of the unique experiences, challenges, and needs of young adult women living with chronic pain. This study also aims to understand how living with chronic pain shapes the identity of young adult women. By understanding the experiences of these women, this study may improve how health care providers approach chronic pain in young adult women.
HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

Two people will take part in this study through the University of Calgary.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you volunteer to participate in this study, the researcher will ask you to do the following:

- Complete three to four in-depth interviews on living with chronic pain. Each interview will be a maximum of two hours in duration
- Complete and/or bring to interviews any journal entries, photographs, voice memos, artwork and other items that you feel reflect your experience living with chronic pain
- Discuss and clarify your experiences through other forms of communication as needed, such as email and telephone
- Interviews will take place in-person, pending current COVID-19 public health orders and measures. If in-person interviews are not possible, interviews will take place by telephone or secure, University licensed web-based videoconferencing such as Zoom.
- Any in-person interviews will be held at a location determined by you and the researcher
- Interviews will be audio-recorded, and may be video-recorded with your consent
- You will be asked to share your experiences living with chronic pain
- Interviews will be focused on your experiences of living with chronic pain

HOW LONG WILL I BE IN THIS STUDY?

Your participation in the study will occur over a maximum of six months. During this time, you will be asked to complete three to four interviews and discuss your interviews through follow-up conversations. The study will require approximately two hours of your time each interview, for a total of three to four interviews. Your total participation will require about twelve hours of your time, including interviews and follow-up conversations to discuss your interviews.

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?

You may experience emotional discomfort if you choose to share experiences that have been difficult for you. You will be provided support resources prior to each interview and referred to community providers as needed. You may also experience physical and/or mental fatigue since there may be an emotional component to the interviews.

Potential COVID-19 Risks:
If interviews are in-person, there may be additional risk related to COVID-19. These risks may include:

- exposure to other people (e.g., research staff)
- risks associated with travel to the interview location (e.g., public transit)

Strategies will be used to decrease the risk of COVID-19 transmission for any in-person interviews. These include:

- screening prior to in-person interviews
- physical distancing measures
- use/provision of personal protective equipment for both research staff and research participants (e.g., masks, gloves)
- use/provision of hand sanitizer for both research staff and research participants
- single use research apparatus where possible (as applicable)
- sanitization of surfaces and multi-use equipment between participants (as applicable)

**ARE THERE ANY POTENTIAL BENEFITS IF I PARTICIPATE?**

There will be no direct benefit to you from participating in this study. However, some participants may find they benefit psychologically from sharing their stories. This study may also help the researchers learn more about living with chronic pain.

**WHAT OTHER CHOICES DO I HAVE IF I CHOOSE NOT TO PARTICIPATE?**

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you. Your decision will not affect the standard medical care you receive.

**CAN I STOP BEING IN THE STUDY?**

Yes. You can decide to stop at any time. Tell the researchers if you are thinking about stopping or decide to stop.

**WITHDRAWAL OF STUDY DATA**

You may request that your data be withdrawn for up to 2 weeks after your final interview.

**WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

You will not be paid for your participation in this research study. You will not be reimbursed for any out-of-pocket expenses, such as parking or transportation fees. However, you will be offered a $50 gift card as an honorarium for your time.
WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?

The researchers will do their best to make sure that your private information is kept confidential. Information about you will be handled as confidentially as possible, but there is always the potential for an unintended breach of privacy. The research team will handle data according the Data Management Plan as outlined below:

- Your name and phone number will be collected for the purpose of contact. This information about you will be stored separately from the research data.
- Any identifiable information about you will be removed or disguised (name, locations, and any other identifying information) in the research data.
- Your name will be replaced with a pseudonym that will be linked to the research data/ records.
- All research data and records will be stored on the University of Calgary network drive using password protection. Any materials shared with other members of the research project will be done so using password protection.
- Only those working with the researcher on the research project will work with the material, and then only with all names, place, and identifying information removed.

The study investigators will make every effort to maintain the confidentiality of your research records, to the extent permitted by law (e.g., disclosed child abuse or neglect must be reported) and legal requests (e.g., court applications seeking disclosure of research data are possible).

HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?

Data and records will be kept for five years from the date the project is closed, then destroyed in accordance with the University of Calgary Data Retention Policy. Data and records will be de-identified, meaning any personal identifying information will not be kept with the research data and records.

WHAT OTHER THINGS SHOULD I CONSIDER BEFORE PARTICIPATION?

CONTACT FOR FUTURE RESEARCH

University of Calgary researchers may contact me in the future to ask me to take part in other research studies.

☐ YES
☐ NO

WHOM MAY I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The Research Team:
You may contact Jenise Finlay or Aniela dela Cruz at 1-403-210-7484 with any questions or concerns about the research or your participation in this study.

**Conjoint Health Research Ethics Board (CHREB):**
If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

**HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?**

Study results are available on request by contacting Jenise Finlay or Aniela dela Cruz at 1-403-210-7484 or jenise.finlay@ucalgary.ca.

**WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?**

Taking part in this study is your choice. You can choose whether or not you want to participate. Whatever decision you make, there will be no penalty to you.

- You have a right to have all of your questions answered before deciding whether to take part.
- Your decision will not affect the standard medical care you receive
- If you decide to take part, you may leave the study at any time

**HOW DO I INDICATE MY AGREEMENT TO PARTICIPATE?**

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to take part in the study. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

**SIGNATURE OF STUDY PARTICIPANT**

Name of Participant

__________________________________________________________
Signature of Participant  Date

**SIGNATURE OF PERSON OBTAINING CONSENT**

Name of Person Obtaining Consent  Contact Number

__________________________________________________________
Signature of Person Obtaining Consent  Date
SIGNATURE OF THE WITNESS

________________________________
Name of Witness

________________________________    ______________
Signature of Witness                  Date

A signed copy of this consent form has been given to you to keep for your records and reference.
References


Bulun, S. E., Yilmaz, B. D., Sison, C., Miyazaki, K., Bernardi, L., Liu, S., Kohlmeier, A., Yin,


