

PERSONAL ILLNESS EXPERIENCE OF MY ADOLESCENT SELF:

A NARRATIVE INQUIRY SELF-STUDY

by

Sophia Aksenchuk, B.Sc.N., 2016

Ryerson University, Toronto, Ontario, Canada

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## **Author's Declaration**

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# PERSONAL ILLNESS EXPERIENCE OF MY ADOLESCENT SELF: A NARRATIVE

## INQUIRY SELF-STUDY

Sophia Aksenchuk, 2020

Master of Nursing  
Ryerson University

### **Abstract**

Building on Dewey's philosophy of experience, our personal and professional lived experiences are mutually informing. Thus, personal illness experiences may impact how we engage in professional roles. In this self-study, using Connelly and Clandinin's Narrative Inquiry, I explore my experience of an eating disorder as an adolescent, and how this experience informs my nursing practice today. I crafted stories of my illness experience often using poetic prose. I analyzed these using the three levels of justification (personal, practical, social) through the theoretical lens of Erikson's psychosocial stages of development. Four narrative threads (*impulsivity: response to losing control, lack of autonomy, liminality, lack of meaningful relationships*) emerged and coalesced into three narrative patterns (*control, belonging, identity*). This self-study provides healthcare professionals an understanding of the impact a stigmatized illness may have on one's professional role. My intention is to inspire others to enter their own inquiry into their experiences of illness.

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## **Dedication**

I dedicate my thesis to all the persons who have ever suffered from an eating disorder or who have ever supported a loved one suffering from an eating disorder. May you find peace, strength, resilience and courage from within. All persons are worthy of love, respect, and belonging.

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## Prologue

I am on an old sailboat  
as it rocks back and forth through turbulent waters.

I check my map to review my course,  
admiring how far I have traveled.

I left my birth-country in eastern Europe, many years ago;  
though it feels like it was yesterday.

I have been lost at sea for many years,  
navigating the uncertainty of open waters, not knowing where to turn.

I am a nomad,  
who was abandoned,  
and lost in the tsunamis of teenage-hood.

The chaotic waves had engulfed my body,  
my mind  
and my spirit,  
countless times.

Despite this suffering,  
I have managed to steer clear of the rocks  
and navigate my way to stable waters.

Having gone through the turbulence,  
I am now in a position to look back where I came from,  
and how that informs who I am today as an adult and as a professional  
(Aksenchuk, 2019).

## **Chapter One**

### **Introduction**

In this chapter I introduce how I began my thesis journey to explore my personal illness experience using Narrative Inquiry. I complete the chapter by charting the course of my thesis process.

In the fall of 2017, Dr. Schwind, my professor at the Master's level at Ryerson University, introduced me to Connelly and Clandinin's Narrative Inquiry (NI) (1990, 2006) a qualitative research method, as well as to studies exploring lived illness experiences. Throughout the course lead by Dr. Schwind entitled Nursing Knowledge, I continued to read stories of lived illness experiences in research literature, as well as in informal media articles. I was inspired by the stories I read. In particular, Schwind's dissertation (2004) resonated with me. In her Narrative Inquiry auto-biography, Schwind explored personal illness experiences of nurse-teachers, including her own. I had also experienced a personal illness during my adolescence. However, I often felt trapped in the memory of my illness, and so avoided reflecting on its role in my life today, although I knew it had one. But, after reviewing the literature I began to feel empowered by the stories I read. I decided to explore my own illness experience, using Narrative Inquiry, qualitative research approach, with the intent to learn how that experience impacts who I am as a professional today.

#### **Lived illness experience and Narrative Inquiry**

To begin my journey, I first explored what it meant to live narratively and how I could possibly share stories that have never been previously told. I began with Dewey's (1938/1963) pragmatic philosophy, which emphasizes the notion that all prior experiences have the power to inform and prepare a person for future experiences when intentionally explored and reflected

upon. While reflecting on his work, I immediately remembered the work of Beck (1967), who suggested the way we think about the world and our place in it influences our behaviours and feelings. Thus, our previous experiences develop our attitudes and assumptions about the world known as schemata. As I further considered these notions, I found myself reaching to Narrative Inquiry (Connelly & Clandinin, 1990, 2006) and began to learn about inquiring into lived and told stories of experience.

More specifically, I learned it is our human nature to live storied lives, to share stories of our experiences, and to make meaning of them, as we live and tell these stories (Clandinin, 2006; Connelly & Clandinin, 1990). In this case, narrative is both the phenomenon and the method (Connelly & Clandinin, 1990, 2006), which is outlined in the Method and Study Design Chapter of my thesis. These stories also have personal, practical, and social justifications. These justifications are explored and critically reflected upon in each of their designated chapters. Thus, the stories are transformed, and new knowledge is revealed, setting the stage for subsequent inquiry puzzles to emerge (Lindsay & Schwind, 2016).

Lived illness experiences merit intentional critical reflection, as we seek to understand the meaning of these illnesses in our personal and professional lives (Schwind, 2003). Adolescent illness, in particular, involves unique challenges, such as the transition of care from paediatric to adult healthcare services (Nicholas, Picone, & Selkirk, 2011). I recognize that adolescence is often a time for self-exploration, growth, and identifying one's personal and professional self in preparation for entering adulthood. However, illness has the power to significantly impact the progress and trajectory of this process, as it presents unique tensions. For example, adolescents seek to obtain independence but, when experiencing illness, they develop a

significant dependence on parents and family to navigate the health care system (Nicholas et al., 2011).

As I reflect on my adolescent illness experiences, I consider myself a “hopeful pessimist” (King, 2003, p. 92), fearing that my stories might not change the world, yet hoping that they will (Clandinin, 2006). I hope that the story of my illness experience will help others struggling with stigmatizing illnesses, such as eating disorders. I hope to inspire them to make meaning of their lived experiences, and thus to ease their struggles. Through this self-study, I also hope to gain insight into how this experience affected my personal and professional self today, and in this way to inform practice and research.

### **My thesis path**

In the following pages, I invite the reader to join me on my exploration of my lived illness experience. This exploration consists of eight chapters, which include this introduction. The eight chapters are bounded by a Prologue at the outset, which appears prior to the introduction, and an Epilogue after the last chapter. Although the reader may choose to read all or selected chapters, the thesis is organized in a sequential way, to show how the content builds upon itself in a thoughtful and logical progression, following the Narrative Inquiry (Connelly & Clandinin, 1990) research approach. In other words, the subsequent chapters are informed by the preceding chapters to guide the reader along the way. The chapters are written in present tense, with the exception of Chapters Four and Five when I explicate the method and inquiry design of my Narrative Inquiry self-study including the steps to support ethics, rigor, data collection, and analysis.

Each chapter begins with an introduction detailing what the reader can expect to learn in the chapter. Sections within chapters are recognized using headings and subheadings. Sections

within chapters are logically organized by sequence of the unfolding inquiry. At the end of each chapter, there is a “Looking Back, Looking Forward” section to summarize what has been done and what awaits the reader in the next chapter. The chapters are organized as follows:

In the Literature Review Chapter, I explore the current academic and research literature on the research topic in order to situate my inquiry. This chapter is where I introduce the inquiry puzzle.

In the Method Chapter, I describe the historical background of Narrative Inquiry, including its key tenets, and analysis framework. In this chapter, I also discuss self-study approach as I use it within Narrative Inquiry.

In the Inquiry Design Chapter, I explain how I respect ethics and rigour in my self-study, as well as the steps I apply for data collection and analysis. In this chapter, I introduce the theoretical lens I apply to enlighten the inquiry puzzle.

In the Personal Justification chapter, I complete the first level of analysis using the multiple “I”s of Narrative Inquiry. I use different font styles to depict my researcher “I” and my participant “I”. This chapter is where I share my lived personal illness stories and engage with the stories as a researcher in present tense.

In the Practical Justification chapter, I complete the second level of analysis. This is where I provide an in-depth description of my theoretical lens and identify the emerging narrative threads and patterns. I analyze these, using the selected theoretical lens, by accessing relevant literature. I end the chapter by considering what has been learned, addressing the inquiry puzzle and why these findings may be significant to the nursing profession.

In the Social Justification chapter, I complete the third, and final, level of analysis. In this chapter, I discuss the potential social implications of this work and possible contributions to practice, education and research.

In the Re-presentation chapter, I address a letter, written in poetic prose, to a young person who may be experiencing their own struggle with a stigmatizing personal illness. I include what I have learned through my Narrative Inquiry self-study and my hopes for those who read it.

The Epilogue is presented as poetic prose, using a metaphor of cliff jumping. This metaphor represents my thesis journey of having lived and shared my personal illness experience for the greater good of nursing practice, education and research.

### **Looking back, Looking forward**

In this chapter, I introduced my growing interest in lived illness experiences and what I intend to explore in my thesis. In the following chapter, I present a review of current relevant literature and my inquiry puzzle that guides this self-study.

## **Chapter Two**

### **Literature Review**

In this chapter, I explore the current body of literature to inform and situate my inquiry puzzle. I begin with a review of personal illness stories. I continue by acknowledging the common assumptions in the literature about eating disorders, and how these relate to my own values and the research purpose of this self-study. In relation to my personal illness experience, I identify three variables informed by the inquiry puzzle; adolescence, as the developmental stage in which the illness occurred; identity formation during adolescence; and, stigma, particularly referring to mental health. I review literature pertaining to each variable and discuss how it relates to this self-study. I conclude the chapter with my inquiry puzzle statement.

In this chapter, *illness* refers to a person's whole lived experience of a medical condition: mind, body and spirit connected. In contrast, the terms *disease*, *diagnosis* and *pathology* refer to the medical model's current identification of medical conditions, which may or may not acknowledge a person's mind, spirit or body.

#### **Personal illness stories**

Although personal illness stories have been present in healthcare research for centuries, they predominantly flourished since the late twentieth century (Armstrong, 2013; Frank, 2002; Hawkins, 1999; Hubbard, 2011; Schwind, 2003, 2004; Sinclair, 2009; Thomas, 2006; Williams, 1995). In the literature, researchers primarily studied patients' lived experiences with chronic illnesses (Jerpseth, Dahl, Nortvedt, & Halvorsen, 2017; Niclas, 2018; Price, 1993; Schwind, Fredericks, Metersky, & Gaudite Porzuczek, 2015; Stanhope & Henwood, 2014) and the experiences of their families (Novosel, 2007; Schroeder, 1998; Whitsitt, 2012). Many studies have been conducted where healthcare providers (Fox et al., 2011; Klitzman & Weiss, 2006), and nurses specifically (DeMarco, Picard, & Agretelis, 2004; Kinney, 1996; Schwind, 2003),

explored and shared their personal illness experiences. Healthcare providers have also reached beyond research to write personal editorials (Olson, 2002), published journal articles (Coulter, 2008; Dowey, 2005; Memon, 2013; Taylor-Marshall, 2002; Tosh-Kennedy, 2007) and create public online blogs (Sczuroski, 2017) about personal illness experiences. By critically reflecting on personal illness experiences, individuals, including healthcare professionals, can make meaning of illness on a personal level, which in turn can inform their professional practice (Amundson & Ross, 2016; Charon, 2001/2004; Himes, 2002; Lawson et al., 2017; Schwind, 2003, 2004; Taylor, 1992; Taylor-Marshall, 2002; Winawer, 1998).

Many healthcare professionals recognize the importance of patients' illness stories, which provide meaning, context and information that would otherwise be lost during a clinical assessment (Borasio & Tamches, 2018; Foster et al., 2016; Gidman, 2013; Last, 2012; Ragan & Kanter, 2017; Schwind et al., 2015). In practice, understanding a patient's lived illness experience promotes person-centered care, as healthcare providers can attune to what individuals value in their care and in their lives (Charon, 2004; Schwind et al., 2015). Furthermore, when healthcare providers explore how patients experience illness, it exposes the patient's unmet needs, such as emotional care, as well as communication regarding grief, prognosis, preferences, and decision-making (Charon, 2004; Jerpseth et al., 2017; Kristofferzon, Lofmark, & Carlsson, 2007). Additionally, studies on illness experiences expose the unique barriers and challenges that persons face when accessing healthcare services, which may help plan programs and policies that improve quality of care for patients (Ensign & Bell, 2004, Schwind et al., 2015). Professionals have used their illness experiences as tools to connect with patients and promote patients' autonomy in managing their illnesses, as well as to make meaning of their experiences

(Goldberg, Hadas-Lidor, & Karniell-Miller, 2015; MacCulloch & Shattell, 2009; Richards, Holttum, & Springham, 2016).

### **Assumptions about eating disorders**

An eating disorder is clinically classified as a mental health disease (American Psychiatric Association, 2013; Government of Canada, 2015), thus it is often associated with stigma, fear, and shame. Even though literature related to patient's lived experience of eating disorder illness focuses on mental health, as identified above, (Dimitropoulos et al., 2015; Lindgren, Enmark, Bohman, & Lundstrom, 2014; Scott, 2008; Tan, Hope, & Steward, 2003), my thesis does not exclusively focus on the experience of mental health, rather I explore my personal experience with an eating disorder during adolescence as a critical life event that continues to impact my development as an adult person and a professional.

Although I acknowledge that the disease process and my experience of having an eating disorder as an adolescent is far more complex than one label can encompass, I must admit that one's state of mental health and well-being is a large component of how eating disorders commence and perpetuate. Early research suggests eating disorders are about gaining a sense of control in adolescence, in addition to worrying about one's sense of self and body image (Bruch, 1978; Micali, Ploubidis, De Stavola, Simonoff, & Treasure, 2014; Rohde et al., 2007). In an effort to build their sense of self, adolescents may engage in eating disorders to feel a sense of control by manipulating their food intake and so changing their bodies (Dignon, Beardsmore, Spain, & Kuan, 2006; Malson, 1998; Reid, Burr, Williams, & Hammersley, 2008). However, this does not resonate with my current understanding of my own eating disorder experience, as I often define it as an addiction. This view supports research that suggests eating disorders become

a way of life and a habit, with the adolescent often exhibiting feelings of ambivalence, as the disorder becomes their identity (Giles, 2006; Ison & Kent, 2010; Weaver, Wuest, & Ciliska, 2005; Williams & Reid, 2010). Over time, eating disorders manifest into a dominant voice within the person, a self-criticizing voice, that leads to a battle within the self (Williams & Reid, 2012). This sustains the disease because the ill person relies on disordered eating to cope and manage the impact of this voice.

Specific to my personal illness experience, three significant aspects of the illness inform my inquiry puzzle, as discussed below: adolescent illness, identity development, and stigma.

### **Adolescent illness**

Living with any serious illness during adolescence presents unique challenges, due to the combined effects of disease and adolescent development (Beerbower, Winters, & Kondrat, 2018; Suris, Michaud, & Viner, 2004). During the developmental stage of adolescence, the person is concerned with autonomy, identity formation, and emerging adult responsibilities (Osgood, Foster, & Courtney, 2010). However, in addition to the usual developmental process, adolescent patients must concurrently navigate development and personal milestones, while managing the burden of illness (Barr, Ferrari, Ries, Whelan, & Blever, 2016). The demands of experiencing illness and ongoing treatment can severely limit an adolescent's quality of life, identity, self-esteem, autonomy, and social life (Groothoff et al., 2005; Roumelioti et al., 2010; Thavakugathasalingam, 2016; Tjaden, Tong, Henning, Groothoff, & Craig, 2012). Some studies found that adolescent patients report poor psychosocial wellbeing when they experience illness, increasing their risk for behavioural problems, worsening mental health conditions, and emotional challenges (Collins, 2011; Geue et al., 2018; Jamieson et al., 2014; Mackner, Sisson, & Crandall, 2004). As most adolescents experiencing illness are noted to have desires and needs

characteristic of their developmental age, research stresses that healthcare providers, when planning their care, should focus on the developmental wellbeing of their adolescent patients, instead of only on the pathology (Bakke, 2016; Beerbower et al., 2018; Taylor, Gibson, & Franck, 2008).

Interestingly, adolescents with psychiatric disorders have additional challenges within their own lived illness experiences, such as self-stigmatization, which can severely impact their self-esteem, self-efficacy, and social interactions (Corrigan & Kleinlein, 2005; Kranke, Jackson, Taylor, Landguth, & Floersch, 2015). Furthermore, youth who experienced an acute psychiatric hospitalization, reported struggling with social relationships, regulating emotions, and academic performance (Preyde, Parekh, Warne, & Heintzman, 2017). One study found that communication by family members and health care providers with the adolescents, including word choice and style, were significantly important to how adolescents experienced their illness (Zebrack, Chesler, & Kaplan, 2010). Family members and health care providers are key stakeholders, who support adolescent patients to make meaning of their diagnosis, understand their illness, and transform their personal and social identities (Cardillo, 2010; Chesler & Parry, 2005; Zebrack et al., 2010). Thus, adolescent illness encompasses complex multidimensional needs that are physical, emotional, and psychosocial (Preyde et al., 2017).

### **Identity development**

Identity incorporates personal components, referring to how people view themselves as unique individuals, and social components, referring to how people view themselves as members of meaningful social groups (Atak, 2011; Baumeister & Muraven, 1996; Hall, McKinstry, & Hyett, 2016; Kirk & Rey-Okazawa, 2006; Marcia, 1966; Ozdemir, Utkualp, & Pallos, 2016; Parisian, 2015; Tajfel, 1981; Turner, Hogg, Oakes, Reicher, & Wetherell, 1987). According to Erikson (1968), identity formation is a central concern of psychosocial personal development in

adolescence, as adolescents attempt to define and develop their role in the adult world. Environmental influences and personal feelings play an integral role in shaping their identity, motivation, decision-making, and confidence (Wigfield & Wagner, 2005). Identity and self-esteem, a construct that refers to personal evaluation of one's worth, are related and reinforced throughout adolescence (Luyckx et al., 2013). Absence of identity, or a poor commitment to one's identity, is strongly related to low self-esteem (Kroger & Marcia, 2011), which is a known risk factor for many psychological illnesses, including eating disorders (Ghaderi, 2001).

The development of personal and social identity is affected by illness, especially among adolescents and young adults experiencing illness. The degree to which persons define themselves in terms of their diagnosis varies (Helgeson & Novak, 2007) However, there is a fair amount of literature that suggests eating disorder sufferers often define who they are by their pathology (Broussard, 2005; Fox & Diab, 2015; Lindgren et al., 2015; Tan et al., 2003). This is a significant factor in the development of self-identity, as the diagnosis becomes the person's central identity and provides a sense of security that hinders recovery, as the person fears who they would be without the eating disorder and the acceptance of identifying with the diagnosis (Broussard, 2005; Tan et al., 2003; Williams & Reid, 2010/2012).

Disease affects how the adolescent views themselves, as well as their perception of how other persons view them. In turn, this affects their prioritization of managing their health and their assumptions about how the diagnosis will affect their future (Charmaz, 1995/2000). Interestingly, Bruch (1982) suggested that eating disorders are caused by impairments in identity development. A major impairment in identity development is failure to find multiple domains for self-definition, often due to controlling guardians or limited opportunities to function autonomously and explore one's sense of self. In these cases, Bruch (1979/1981) argued that

adolescents focus on body image, an accessible and controllable, culturally valued domain, as a maladaptive response to feelings of powerlessness and a lack of self-identity. A negative body image, or negative self-schema, is an identity impairment involving a significant dissatisfaction with one's self, predominantly one's physical appearance, that is strongly associated with perpetuating the symptoms and behaviours of eating disorders that provide short-term relief from intolerable inner conflicts (Casper, 1983; Corning & Heibel, 2016; Stein & Corte, 2007). Furthermore, eating disorder symptoms are often associated with feelings of insecurity, social anxiety, social isolation, and interpersonal deficits that hinder positive construction of social identity (Schutz & Paxton, 2007; Stein & Corte, 2007; Zaitsoff, Fehon, & Grilo, 2009). In other words, if one is unable to situate themselves in constructive or healthy social circles, it results in poor identity development where one feels lost or uncertain about who they are, leading to maladaptive coping, such as disordered eating. Thus, poor identity development and eating disorders are mutually informing, where a poor sense of identity can promote disordered eating behaviours and eating disorder pathology can further promote negative self-identity and poor social development.

### **Stigma**

Another factor affecting identity formation related to this inquiry puzzle is the stigma associated with disease, particularly eating disorder as a mental health condition. Stigma and its relation to professional practice is discussed in the following section.

#### **Stigma associated with mental health**

The experience of stigma can affect one's personal and social identity. Prejudice, stigma, and discrimination associated with mental health can impede one's social identity development, since stigma can restrict a person's capacity in work, living, health, and relationships (Gibb,

Fergusson, & Horwood, 2010; Moses, 2014). In the literature, adolescents with mental health conditions report that their experience of stigma prevented positive community engagement, social relationships and treatment seeking (Eisenberg, Downs, Golberstein, & Zivin, 2010; Gruttadaro & Crudo, 2012; Gulliver, Griffiths, & Christensen, 2010; Moses, 2014). In some cases, persons with mental illness internalize frequent social stigma and prejudice leading to self-stigma, shame and ambivalence, thus further demeaning their self-worth, promoting a low self-esteem and developing a negative self-identity (Corrigan & Rao, 2012; Livingston, 2010). This limits access to most social groups and belonging, which is reported of value to adolescents (Erikson, 1982). On the other hand, stigmatized identities, such as those associated with mental illness, are shared identities that may promote a maladaptive source of support and belonging that comes with group membership (Branscombe, Fernandez, Gomez, & Cronin, 2012).

Identity formation, as a dominant adolescent milestone, is affected by disease and stigma, as it excludes affected persons from fulling engagement in social groups, norms, and belonging. To cope with illness, persons must understand the illness experience by finding meaning in the condition with regards to their story, world, and life (Commissariat, Kenowitz, Trast, Heptulla, & Gonzalez, 2016).

### **Stigma and professional practice**

The impact of personal illness experiences on professional practice has been explored in research, often referring to healthcare providers with personal illness experiences as wounded healers (Conchar & Repper, 2014; MacCulloch & Shattell, 2009; Zerubavel & Wright, 2012) or wounded storytellers (Frank, 2013), motivated by their own experiences to help others. For some persons, a prior illness experience was found to be a motivating factor to become a healthcare provider (Kidd, 2008; Oates, Drey, & Jones, 2017). Despite the perceived benefit that wounded

healers have the capacity to provide better care, based on their personal insight into illness experience (Zerubavel & Wright, 2012), there are many barriers and challenges associated with sharing stories of personal illness. Specifically, sharing stories of a mental illness experience within a professional setting is associated with concerns about professional competency, often resulting in bullying (Kidd, 2008; Moll, Eakin, Franche & Strike, 2013). This further perpetuates the individual's sense of vulnerability, as well as the stigmatization of mental health conditions.

Likis (2014) stresses that healthcare professionals share the responsibility to address the shame and fear that surrounds mental health. Similar to Likis, Peterson (2017) concludes that an important way nurses can challenge assumptions and stigma of mental health is by sharing their personal illness stories. Furthermore, Oates et al. (2017) studied how mental health nurses' personal illness experiences informed their professional practice. The study reveals that personal illness experience impacts professional practice in three ways: developing positive patient relationships, understanding patients' needs, and motivating potential nurses to join the profession. Along with Likis (2014) and Peterson (2017), Oates et al. (2017) acknowledge that there is a stigma among nurses sharing stories of prior or current mental illness experiences. However, healthcare professionals need to share their stories to address stigma and recognize how these unique experiences enhance our nursing expertise and professional identities (Oates et al., 2017). Matthews (2006) believes that stories have the capacity to inspire change in our beliefs and behaviours, thereby reducing stigma associated with mental health.

### **My contribution**

According to the reviewed literature, experiencing a stigmatized illness, such as an eating disorder, during my adolescence impacted my growth and development during that stage of my life, and continues to inform my current adult personal and professional self. Based on the

review of literature and research that has been completed to date, and on my own experience of an eating disorder during adolescence, I undertake this self-study to critically analyze the impact of this traumatic event in my life today, as a person and as a nurse. To achieve this, I use a Narrative Inquiry qualitative approach (Connelly & Clandinin, 1990, 2006; Lindsay & Schwind, 2015; Schwind, 2008).

My inquiry gives voice to the experience of an eating disorder during adolescence. Thus, my self-study has the potential to augment the research literature on how adolescents experience illness, particularly the ones that carry a stigma, and what could be gleaned from such investigation. Additionally, my inquiry provides a window for other healthcare professionals to learn what it may mean to experience a stigmatizing serious illness during adolescence and to carry that trauma into adulthood, and specifically into the healthcare profession.

### **Inquiry Puzzle**

*How does my personal illness experience with an eating disorder during adolescence impact my professional self today?*

### **Looking back, Looking forward**

In this chapter, I provided an overview of existing literature to inform and situate my inquiry puzzle. Moving forward, in the next chapter I explicate the method Narrative Inquiry, and specifically as it relates to the self-study design.

## **Chapter Three**

### **Method**

I begin this chapter by discussing the historical background of narrative inquiry, specifically Connelly & Clandinin's Narrative Inquiry (1990, 2006). To further explain Narrative Inquiry, I discuss the key tenets, the three-dimensional space of Narrative Inquiry, and the three levels of justification. I explain the analysis stage of my study and complete the chapter with an overview of the principles of self-study research. In my work, I capitalize Narrative Inquiry to recognize Narrative Inquiry as a distinct method created by Connelly and Clandinin (1990) among the various other approaches of narrative research (Lindsay & Schwind, 2016).

Connelly and Clandinin (1990) were first to use the term *narrative inquiry*. Their conceptualization of Narrative Inquiry is inspired by Dewey's (1938) philosophy of experience, which suggests that life is education, and education is life. Dewey also believed that experience happens over time in a place and in relationship. Connelly and Clandinin (1990) apply these conditions in their extensive work as the three-dimensional space of experience, which is discussed later in this chapter.

#### **Historical background of Narrative Inquiry**

Within narrative research, Narrative Inquiry as a method appears novel. However, it "has 'realist', 'modernist', 'postmodern' and constructionist strands" (Kohler Riessman & Speedy, 2006, p. 428). Prior to 1990, MacIntyre's (1981) concept of narrative unity, Mitchell's (1981) extensive presentation of narratology, Polkinghorne's (1988) knowledge of narrative analysis, and Cole's (1989) narrative literature, reflect characteristics of Narrative Inquiry. Thus, Narrative Inquiry is considered to be cross-disciplinary, surpassing "the boundaries of any single scholarly field" (Kohler Riessman & Speedy, 2006, p. 427). Inspired by those who came before them, Connelly and Clandinin (1990) established Narrative Inquiry as a research method and

framework for exploring lived experiences (Clandinin, Pushor, & Orr, 2007). Their work is part of the “narrative revolution” that emerged in response to the decline of an exclusively positivist paradigm within the research of social sciences (Lieblich, Tuval-Mashiach, & Zilber, 1998).

Narrative Inquiry is hermeneutical and supports the inquiry aim within the constructivist paradigm, to seek understanding and reconstruction of lived experiences (Guba & Lincoln, 1998). Clandinin and Rosiek (2006) suggest that the constant variable across the varying narrative approaches is the study of experience. Clandinin and Connelly’s (2000) definition of Narrative Inquiry, is a “way of understanding experience” (p. 20). In order to gain an understanding of the experience, the researcher must play an active role in exploring their own biases, assumptions, values and beliefs, throughout the collected stories of the phenomenon under investigation (Connelly & Clandinin, 2000; Clandinin, 2006; Silko, 1997).

### **Connelly and Clandinin’s Narrative Inquiry**

In this section, I explore how Clandinin and Connelly (2000) developed their method of Narrative Inquiry, inspired by researchers before them. I first share the work of prior scholars that inspired and informed Clandinin and Connelly to practice narrative research. Then, I share how Clandinin and Connelly (2000) borrowed from prior authors to create their approach to Narrative Inquiry.

Clandinin and Connelly (2000) recognize personal experiences as valuable learning opportunities worthy of exploration. Oakeshott (1962), Schon (1983), and Johnson (1987) inspired Connelly and Clandinin to think more narratively. For Schon (1983), experience is central to reflective practice, as reflected-upon experience becomes knowing-in-action. For Oakeshott (1962), technical rationality is grounded on a need for certainty, that attempts to eliminate biases, outlooks, attitudes, and prejudices. He stresses that science, similar to art,

cannot be reduced to technique, as practice is more complex than the execution of skill. With regards to technical rationalism, Johnson (1987) used the term objectivism to imply that no matter what a person happens to believe, there is one correct way to view the world. Johnson suggested that objectivism depersonalizes the truth and meaning of experience, as technical rationalism seeks to find certainty. However, “emotion, value, felt experience with the world, memory, and narrative explanations of one’s past do not stand still in a way that allows for certainty” (Clandinin & Connelly, 2000, p. 37). In other words, to think narratively is to accept the uncertainty of experience and to engage with personal biases, beliefs and assumptions rather than separating them.

To create Narrative Inquiry, Clandinin and Connelly (2000) borrowed from the works of five scholars, specifically: Polkinghorne’s (1988) and Czarniawska’s (1997) works offered the possibility of adapting theories, metaphors, and terminology from various disciplines, informing the connection between research and practice. Whereas, Coles (1989), Bateson (1994), and Geertz (1995) provided more inherent narrative concepts. Coles (1989) inspired narrative thought through teaching and learning within psychiatry, encouraging attention to be given to the stories that educators and students share. Bateson (1994) stated that what researchers write about people and events, is always open to revision and change. Thus, Clandinin and Connelly (2000) felt that Bateson’s perspective offered them the notion that “to do good research, one needs to be a good human being” (p. 17).

Furthermore, Geertz (1995) used the metaphor of a parade, showing it was impossible to observe an experience as an isolated event. Rather, one must observe it embedded within the whole context of the metaphorical parade. By retrospectively observing his experience within the field of anthropology, Geertz (1995) introduced tentativeness in Narrative Inquiry in two ways.

The first notion of tentativeness refers to our positioning in the parade. The second notion stresses that as the parade changes, our relative position changes as well. Thus, what we know to be true in one point in time shifts as the parade moves to another point in time (Clandinin & Connelly, 2000). Geertz's (1995) work, along with that of Dewey (1938), inspired the Narrative Inquiry three-dimensional space of experience, discussed in the next section.

### **Key tenets of Narrative Inquiry**

Narrative Inquiry as a method requires us to view experience as the phenomenon to be studied (Connelly & Clandinin, 1990). According to Clandinin and Connelly (2000) Narrative Inquiry "is stories lived and told" (p. 20) and is a way of thinking about experience. Narrative Inquiry is often referred to as "a form of living [and] a way of life" (p. 78). The key terms in Narrative Inquiry are experience, story, and narrative. In Narrative Inquiry, experiences are life events that provoke critical reflection. Story is a method (Connelly & Clandinin, 1990), an instrument (Bruner, 2002), or simply a re-presentation (Craig, 2005) to convey experience. In other words, story is the way in which persons interpret their world and make their experiences meaningful (Connelly & Clandinin, 1990). Narrative is a phenomenon and a method for living, collecting, telling and writing about experience (Connelly & Clandinin, 1990). The key tenets of Narrative Inquiry are the three-dimensional space of experience, and the three levels of justification.

### **Three-dimensional Space of Experience**

Clandinin and Connelly (2000) consider the three-dimensional space of experience the theoretical framework of Narrative Inquiry through which experience is explored in the *field*, written about in the *field text*, and analyzed to compose *research text*. It is heavily influenced by Dewey's (1938) pragmatic philosophy and consists of temporality, sociality, and place.

**Temporality.** The dimension of temporality is a central component of Narrative Inquiry. It means that experiences happen over time, with a fluid movement between the past, the present and the future (Clandinin & Connelly, 2000; Lindsay & Schwind, 2016). Clandinin and Connelly (2000) use the term temporality to represent the continuity of experience, as informed by Dewey's (1938) philosophical perspectives. The concept of continuity was discussed by Dewey, as a criterion of experience, where present experiences are born from other experiences, and lead to future experiences. Later, Geertz (1995) and Bateson (1994) wrote about their lives as anthropologists, highlighting change as a characteristic of life. Geertz (1995) provided the most substantial support for continuity, as for him change over time represented his view of anthropology. For Bateson (1994) learning is change, and continuity is possible through improvising, adapting, and learning. In other words, inquirers often find themselves in the *midst* of stories, positioned on the continuum of experience, whether that be the present, past, or future, where each point is based on experiences leading to new experiences (Clandinin & Connelly, 2000).

**Sociality.** The dimension of sociality involves the social and personal context of experience and is based on Dewey's (1938) criterion of interaction. In other words, persons are individuals, but always in relation to social settings (Clandinin & Connelly, 2000). Clandinin and Connelly (1994) first discussed the notion of interaction as four directions in an inquiry: inward and outward, backward and forward. *Inward* refers to the internal conditions, such as hopes, morale, and feelings. *Outward* is directed at the existential condition, or the environment. Lastly, *backward* and *forward* suggests continuity, thus the past, present and future. Narrative Inquiry requires inquirers to simultaneously experience and ask questions directed in these four directions (Clandinin & Connelly, 2000).

**Place.** In their earlier work, Clandinin & Connelly (1994) wrote only about two dimensions, continuity and interaction as informed by Dewey's (1938) philosophy. However, place, also known as situation, was soon after noted as a third dimension, representing the physical and imagined boundaries of the landscapes of an inquiry (Clandinin & Connelly, 2000). The "self" as the inquirer and the "self" as the participant are both situated within this landscape. Both perspectives of "self" inform, and are shaped by the landscape (Clandinin, 2006; Clandinin & Connelly, 1998). Within this dimension, it is also possible to find locations or settings within the stories that bring further understanding or meaning to the experience (Wang & Geale, 2015).

### **Three Levels of Justification**

The process of Narrative Inquiry involves three levels of justification: personal, practical and social (Clandinin & Connelly, 2000). The three levels of justification enter the study at two different times: first at the beginning of the inquiry and then again at the analysis stage. As each level is discussed further, I present how each level is satisfied at these two stages of the Narrative Inquiry process.

#### **Personal justification**

At the personal justification level, the researcher enters their own inquiry, inspired by fragments of participants' stories or fragments of their own stories, such as in this self-study.

*At the start of the inquiry:* Personal justification is represented by a story of how the inquirer comes to study the chosen phenomenon. In my self-study, I share an account of my personal illness experience as an adolescent. By engaging in this process, as an inquirer, I also consider the broader purpose of my scholarly undertaking, in other words questioning why this experience is important.

*At the analysis stage:* As I am both the inquirer and the participant in this self-study, I share my personal illness stories in the personal justification chapter. I write the stories using a special font to distinguish my voice as a participant in the study. Once the stories are written, I interject at certain fragments of the stories, distinguishing my “self” as the inquirer using a different font style. In this way I apply the multiple “I’s” of Narrative Inquiry (Clandinin & Connelly, 1998).

### **Practical justification**

Engaging in the practical justification involves reaching beyond the self and considering how the inquiry is situated within scholarly literature. Also, the sphere of consideration expands beyond the personal to encompass the greater professional circle (Lindsay & Schwind, 2016).

*At the start of the inquiry:* The inquirer engages in what is akin to the traditional literature review, revealing what other research has been done on the topic to identify and support the value of the narrative inquiry. In other words, practical justification is satisfied when I identify where the current study augments the current research and how its outcomes may contribute towards further knowledge development.

*At the analysis stage:* Based on the emerging narrative patterns, the inquirer considers which theoretical lens would best help address the inquiry puzzle (Lindsay & Schwind, 2016). It may be that the 3-dimensional space of experience is sufficient, or it may be another suitable theoretical lens. Thus, practical justification at the analysis stage depends on what emerges from the told stories. Additionally, as the inquirer in this self-study, I consider how the inquiry may impact the nursing profession and healthcare, stretching beyond the personal impact.

## **Social justification**

The social justification refers to a more global perspective of the experience and its impact on the greater social environment. In other words, how the insight gained from the inquiry informs research, education, and practice (Lindsay & Schwind, 2016). This relates to the invitational quality of rigorous Narrative Inquiry. In other words, social justification is supported if I write my Narrative Inquiry with the intent to inspire others to engage in exploration of their own lived experience.

*At the start of the inquiry:* Social justification is addressed by answering why this topic may be significant to the greater society and/or humanity. For example, in consideration that many adolescents experience eating disorders, as an inquirer of this self-study, I must consider how my inquiry could help other individuals and their families struggling with this illness. I also need to think of how my self-study could inform the practice of my professional peers when looking after patients with stigmatized illnesses. Thus, as I begin my study, the hope is to enhance the quality of person-centred care of adolescent patients, as well as to consider how this inquiry may contribute to the support of patients, families, and healthcare providers.

*At the analysis stage:* Social justification is satisfied by answering, “Why is this important to the greater society?” For example, as I analyze my stories, I may answer this question by considering how my narrative may impact nursing education, the delivery of person-centred care of adolescent patients, the quality of adolescent patient experiences, and what further research could take this work forward.

## **Self-study**

Self-study research emerged from three components within educational research (Bullough & Pinnegar, 2001), described here in a non-sequential order. One component is the

introduction and growing popularity of qualitative and naturalistic research, as well as the later work of Lincoln and Guba (1985). Another component is the growing belief that one always teaches the self. This notion was inspired by Pinar's (1980, 1981) self-exploration or "currere", which further influenced the search for self-understanding and education. The final influence is that of participatory action research and the development of models for research that blur the boundaries between researcher and participant (Cochran-Smith & Lytle, 1993). As a result, these components promoted and encouraged a natural process of studying one's own practice. These influences merged in the nineteen-eighties, when the work of self-study began to grow. However, this new approach struggled for legitimacy in the research world (Bullough & Pinnegar, 2001), and to some extent it still does.

Bullough and Pinnegar (2001) noted that "ultimately, the aim of self-study research is moral, to gain understanding necessary to make interaction increasingly educative" (p. 15). It encourages scholars to turn inward in their education and embark on journeys to connect and share their personal and professional selves with others (Shields, Novak, Marshall, & Guiney Yallop, 2011).

Shields et al. (2011) wrote stories, using Narrative Inquiry self-study approach, about their own experiences as graduate students, while exploring imagined places in their present and future lives, discussing how thinking narratively had become a way of life. More recently, Kwok (2017), early childhood educator, applied a self-study design using Narrative Inquiry to reflect on her lived experiences of immigrating to Canada as a child and how it has impacted her personal and professional self today. Her work is part of a growing mosaic of self-study research, that has become a way of life for scholars, with multiple benefits including finding their voice (Belenky, Clinchy, Goldberger, & Tarule, 1997; Marshall, 2002; O'Donoghue, 2014; Yi, 2018),

informing their professional practice (Conway, Palmer, Edgar, & Hansen, 2016; Coral, 2011; Marshall, 2009), and understanding their life, which often involves a change of perspective (Griffiths, 2010; Guiney Yallop, 2008; Meskin, & van der Walt, 2018; Samaras, 2010).

Mooney (1957) argued that all research is a personal venture that has social benefits. This perspective aligns well with the philosophical underpinnings of Narrative Inquiry (Connelly & Clandinin, 2006). The notion of “who we are as people is who we are as practitioners” (Lindsay, 2008, p. 32) speaks to the importance of personal knowing through critical reflection on personal stories.

Self-study research does not focus on the self, but rather “on the space between self and practice engaged in” (Bullough & Pinnegar, 2001). Thus, researchers engaging in self-study must tirelessly balance self and practice with self in relation to practice and with those who share the practice setting. I share this relationship at the Social Justification level of analysis, where I explain how my study may impact practice, education and research. This is vital in self-study research because it demonstrates that the study is able to move scholarship and practice forward, not only satisfying one’s own practice (Bullough & Pinnegar, 2001).

### **Looking back, Looking forward**

In the next chapter I focus on the inquiry design. The chapter includes a discussion on ethics, strategies for collection of field text and the approach I use for analysis.

## **Chapter Four**

### **Inquiry Design**

In this chapter, I describe the inquiry design of my self-study. I begin with a focus on research ethics, specifically Clandinin and Connelly's (2000) Narrative Inquiry criteria to support rigour. Next, is a brief explanation about how reflexivity is supported in this self-study. I continue the chapter with a discussion on how field text was constructed and analyzed to compose research text.

### **Ethics**

Guided by relational ethics (Clandinin & Connelly, 2000), Huber and Clandinin (2002) acknowledge that narrative inquirers must think in responsible ways in order to promote safe and ethical research practice. Like in any research, transparency of the study purpose and process are vital to creating ethical research practice in self-study (Wang & Geale, 2015).

Before undertaking this self-study, I completed a short-form Research Ethics Board (REB) protocol and received the Board's approval (Appendix A). As this is a self-study, I am the only participant in my study. Careful consideration is given to protect the identities of others who may be mentioned or affected by my inquiry. Thus, I use pseudonyms for any persons referenced throughout the study. Locations of events described in my stories remain anonymous, using only broad geographical data (e.g. urban hospital in southern Ontario).

### **Criteria to support rigour**

Clandinin and Connelly (2000) identified "wakefulness" as the most vital characteristic when living out a Narrative Inquiry. Clandinin and Connelly (2000) address rigour and reflexivity by asking "What makes a good narrative inquiry?" (p. 185). In response, they

suggest a good narrative has an explanatory quality, authenticity, adequacy, and plausibility. In the following subsections, I describe the criteria and how I use them in my inquiry.

**Explanatory quality.** Inspired by Polkinghorne (1988), an explanatory narrative illustrates the causal connection of events and provides sufficient narrative accounts that support the connection. In other words, a good narrative provides rationale for how events relate to one another in addition to the recollection of events themselves. Thus, an explanatory quality supports the temporality of lived stories and how lived experiences are affected by past, present, and future contexts (Clandinin & Connelly, 2000). In order to meet this criterion, I provide sufficient detail to explain my stories and the analysis, so that the reader can follow the logical progression toward my concluding statements and propositions.

**Authenticity.** An ethical narrative inquiry honours storied lives as they are shared and written (Clandinin & Connelly, 2000). The criterion of authenticity refers to being accurate and truthful about the told stories shared by participants. In this self-study, I remain truthful with regards to the dialogue between myself-the-inquirer and my self-the-participant. This involves avoiding the urge to alter my narrative in order to resolve any possible tensions that arise as the research text is composed.

**Adequacy.** The criterion of adequacy refers to providing sufficient information and detail to appropriately capture the lived experience and address the inquiry puzzle. This is supported in the study, along with the explanatory quality, by providing sufficient detail to appropriately describe the lived experience and address my inquiry puzzle.

**Plausibility.** The criterion of plausibility refers to being reasonable and probable throughout the study. As I engage in writing, reflecting and re-writing my lived illness

experience, I ensure each stage of the research process is initiated, explained, and implemented in a logical way that supports the intention of addressing the inquiry puzzle.

### **Reflexivity**

Reflexivity involves introspective reflection on personal and professional experiences related to the inquiry puzzle. This is satisfied by internal examination, the inward direction of the Narrative Inquiry process, at the onset and throughout the entire inquiry (Lindsay & Schwind, 2016).

### **Theoretical Framework**

In Narrative Inquiry, the three-dimensional space of experience is considered a theoretical framework through which experience is examined. However, based on the lived and told stories, another theoretical lens may emerge that may more fully enlighten the inquiry puzzle. In this self-study, I use Erikson's Theory of Psychosocial Development, also referred to as Erikson's psychosocial stages (Erikson, 1963; 1982). This theoretical lens allows me to more fully examine the lived and told stories of my illness experience, which occur at various points on my early life trajectory, affecting critical transitions of my growth and development.

Although Erikson's Theory of Psychosocial Development is critiqued for its strict linear sequence, I apply this theory with the intention to demonstrate that even the most robust and sequential models, theories and interventions within research and healthcare systems, can be adapted for person-centred critical reflective analysis. By considering different developmental stages of human psychosocial development, I am able to explore how my personal and professional identity is formed throughout the evolving trajectory of a stigmatizing illness, such as an eating disorder.

## **Design**

The inquiry design is guided by Clandinin and Connelly's (2000) Narrative Inquiry research framework, including the three-dimensional narrative inquiry space along with the four directions of inquiry. As discussed earlier, the three-dimensional space of experience consists of temporality, sociality, and place. When working within this three-dimensional space, I may find myself as always being in the midst, "located somewhere along the dimensions of time, place, the personal, and the social" (Clandinin & Connelly, 2000, p. 63). With respect to the four directions of inquiry, I research my experience by simultaneously asking questions and thinking in all four directions, including inward and outward, backward and forward. I direct my inquiry inward, considering my hopes, feelings, and reactions, and observe the outward in consideration of the environment and the social milieu. Concurrently, I direct my inquiry backward and forward, referring to continuity, of the past, present, and future contexts of my stories.

### **Being in the field**

As a narrative inquirer, engaged in a self-study, I am both a character within, and a researcher of, my stories. I enter the inquiry field in the midst of living my stories and examining my life in motion (Kerby, 1991). The field refers to the landscape of my stories, specifically my lived illness experience as an adolescent. The field is also where I as the researcher may experience shifts and changes as I live, tell, relive, and retell my stories. Thus, I maintain flexibility and openness to the ever-changing landscape, as I re-evaluate my understanding of my lived stories (Clandinin & Connelly, 2000).

## **Composing field text**

In the field, I have a dual role, as the inquirer experiencing the experience and being a part of the experience itself. As a result, I scribble in notebooks and transcribe via computer my descriptively oriented observations of my experience in the field. Essentially, these records are creative descriptions of events, happenings, attitudes, and feelings that capture specific moments in the Narrative Inquiry space (Clandinin & Connelly, 2000). These notations include a mixture of details, such as my actions as a character in the stories, my actions as a researcher analyzing these stories, and descriptions of the surrounding physical environment, feelings, and memories of these past times.

By writing field text, I create a richness and complexity to the puzzling landscape, or in this case personal illness experience, that memory alone may not construct (Clandinin & Connelly, 2000). I address my inquiry puzzle by composing field text, which consists of fragments of my lived illness experiences as an adolescent. Thus, I recognize, as a narrative inquirer, that my stories are autobiographical, meaning they are a particular reconstruction of my lived illness experience, acknowledging there could be other reconstructions (Connelly & Clandinin, 1988). This is often termed as implied relativism, meaning persons each have their own interpretation of events that are all equally valid. However, in my self-study, it is my own memory and interpretation of experience that serves the reconstruction. Despite relativism, there are better and poorer interpretations of history, and to present a strong Narrative Inquiry requires a clear and apt moral message. Thus, I strive to continuously refer to field text to avoid subtle meaning, doubtful explanations, and ambiguous conclusions (Clandinin & Connelly, 2000).

My field notes are organized to include words, lyrics, drawings, quotes, and metaphors that represent my feelings, thoughts, and values of my personal illness experience. Most of my

field notes are written by hand or typed in personal emails I send to myself, which are later transcribed into Microsoft word. I attach my reflections in response to reading and re-reading these entries (Summer, 2018) using sticky notes. As I compose field text, I concentrate on the three-dimensional space. This means, I focus on the details of place, nuances of time, and the complex relationships of personal and social observations. By watching outward and turning inward, I compose text that includes details of my personal lived illness experience, as well as my feelings, doubts, uncertainties, and reactions as the researcher.

### **Analysis**

I shape the story of my lived illness experience as an adolescent, and my experience shapes my understanding of who I am today as an adult. Narrative Inquiry is understood as a continual reformation of inquiry, rather than a process for defining and solving a problem (Clandinin & Connelly, 2000). Thus, my Narrative Inquiry is a reconstruction of the lived and told stories of my adolescent illness experience, which continue to evolve and change as the inquiry progresses and as plotlines are continually revised and reconstructed (Clandinin & Connelly, 2000). The process of analysis and interpretation used to transition the field notes to research texts is a complex shifting process, rather than a sequence of steps. Consequently, the development of research text involves various strategies, along with multiple different kinds of interim texts and endless rereading of field texts.

**Transition of field texts to research texts.** For narrative inquirers, it is important to express a connection between one's personal interests and a sense of significance and the larger social concerns articulated in other persons' works and lives (Clandinin & Connelly, 2000). In the transition between field text to research text, I consider why narrative inquiry was selected as the process and how it shifts the social and theoretical conversations of the explored

phenomenon. This transition may be difficult as it requires endless hours of reading and rereading field text to construct a chronicled account of what is present in various field notes to compose concise research text (Clandinin & Connelly, 2000). Research text is developed from a relentless search for personal meaning and social significance, while noting emerging narrative patterns within and across the stories.

Positioning field text within the three-dimensional space of Narrative Inquiry is one way I transition and reconstruct field text into research text. Contextualizing the work socially and theoretically is another way I support the transition of field text into research text (Clandinin & Connelly, 2000). This positioning involves questioning the social significance of my work, specifically in relation to other ideologies, thoughts, and other inquiries and/or research. I accomplish this by applying the three levels of justification, as informed by Lindsay and Schwind (2016) and discussed earlier in this thesis, to consider the personal, practical and social levels of justification within this self-study.

### **Looking back, Looking forward**

In this chapter, I explicated the inquiry design of my Narrative Inquiry self-study, which encompasses the processes and steps with regards to ethics, rigour, reflexivity, and design to explore my inquiry puzzle. In the next chapter, I focus on Personal Justification, the first level of justification.

## Chapter Five

### Personal Justification

In this chapter, I share my personal experience of illness, as my researcher-self interjects responses to my lived and told stories. This is known in Narrative Inquiry as the first of the three analysis stages or justifications: personal, practical and social (Clandinin & Connelly, 2000).

Stories of my illness experience, including preambles, settings and conclusions of the told stories, are written in *Lucida calligraphy* font, size 10. *Lucida* is a term from the Latin phrase *stella lucida* meaning “bright star”. It is traced back to the Latin word *lūcēre*, meaning “to shine”. I chose this font for my stories because growing up, my nickname at home was *Сонце*, the Ukrainian term for *sun*, playing off my eastern European name Софія. I continue to feel close to this nickname, at least within my personal self, to represent what I enjoy being within the world, a shining light. Thus, my stories written in this font represent my identity and my point of view, as the participant living through a personal illness. Within my illness stories, I emphasize specific recalled events using bold *Lucinda calligraphy* font size 10. By sharing a story within a story, I draw attention to the essence of my illness experience.

My researcher “I” continues to be recognized by the Times New Roman font, size 12, as I engage in dialogue with my participant “I”. By combining these fonts, I, visually on paper, distinguish myself as the participant from myself as the researcher, an important distinction in a Narrative Inquiry self-study.

### A brief reflection

Prior to writing this chapter, I found personal journals dating back to my adolescence. I hoped they would prompt a deeper exploration of my inquiry puzzle. However, upon my review of these journals, I found that I barely wrote anything about “it”, my illness, even during its acute

phases. I never called my illness by name. Even to this day, I fear naming “it” in writing. Perhaps it makes the “it” too real? Perhaps by calling “it” *bulimia*, I admit defeat? I feel shame for fearing the stigma and for allowing “it” to have so much strength and control over me; stifling my words, even today.

I feel suffocated by *it*. For a long time, I believed my eating disorder was a sign of weakness that I must hide from the world. Even during treatment, as an eating disorder patient, I was hidden in a hospital, no longer attending school. I was separated from the other patients in a specific ward, located between the out-patient clinic and the acute in-patient unit. I was put in a category that was selected based on their, healthcare providers’, interpretation of the severity of my suffering.

Today, I feel ready to face the impact of my illness. Through the multiple I’s of Narrative Inquiry (Clandinin & Connelly, 2000), I am now able to reflect on the different roles I assume in society and in relation to my illness. My stories are constructed in such a way as to reflect, as close as possible, the inquiry puzzle within the three-dimensions of experience: continuity, sociality and place. In this chapter, I share the stories of events related to my illness experience that stayed prominently in my memory, as I recall having lived them.

### **Stories of my experience with an eating disorder**

The following are what I recall as significant nodal events in my young life that amass to my experience of having an eating disorder as an adolescent.

#### **Clear the plate**

*As a toddler, I am very adventurous and mischievous. I am hungry for life with an insatiable curiosity. Despite wanting to play alone, I am closely guarded. My parents and grandparents, hardworking immigrants from eastern Europe, fear the unfamiliarity and uncertainty of our new life in Canada. In an effort to raise*

*us within the values and beliefs of our traditional roots, our grandparents visit, one at a time, to take care of my sister and me and to teach us, as much as they can, about our family and heritage. They teach us never to waste food and to always follow rules. At one such visit, grandfather (“dido”) is looking after me...*

*“You cannot play until you clear your plate. You must eat!” says dido. It is a warm summer day and all I want to do is play. I do not want to get in trouble, so I sit in the kitchen with my dido. The plate is hot with a heap of stew made with hretchka (buckwheat) and “stinky” meat. I do not want to eat this. I am hungry for adventure, not food! We sit in the kitchen for an hour. Dido finally gives up and lets me go play. He looks angry, but I am not hungry. I say “no” (and mean it).*

*As a toddler, I am tenacious and fearless. I grasp freedom and control whenever I can. However, I fear the consequences of standing up for myself. The strong authorities that raise me demand respect and obedience. Eventually, as I grow, it wears me down. I give up on freedom and I stay at home more and more. In due course, I clear every plate in front of me and gain a lot of unhealthy weight.*

**Researcher-self:** Independent play was important to me as a child. Perhaps it relates to my developmental age, wanting to explore my environment and feel free to push boundaries and to be independent. Seeking independence seemed to take a lot of energy out of me and so it was easier to eventually give in than to continue to fight. I wonder if I consumed these feelings for adventure. Did food become the consolation prize and fill the void of freedom and adventure I desperately yearned for?

### **Three epiphanies**

*For me, my childhood is marked by three epiphanies: the first time I became aware of my body, the first time I remember feeling deep loneliness, and the first time I learned the importance of social connections.*

**Researcher-self:** What is it about firsts in childhood? Why not the third, fourth, or ninth event?

Perhaps these mark a milestone? Perhaps the first memory may be the most powerful ... or painful, and all subsequent episodes become progressively tolerable?

**The bus-ride.** *I ride a bus to and from school. Most rides are uneventful. I experience repeated episodes of bullying at school ... on the playground, in the classroom, and on school trips. This particular bus ride seems different. It is the first time (sadly not the only time) that the bullying is blatantly direct.*

*“Why are you so fat?” asks the boy from my class. I think to myself, “That’s not a question! That’s an insult!” I feel a lump in my throat, but I manage to mumble, “Are you saying I’m fat?” The boy laughs. Suddenly, the bus halts, and the boy exits the bus. After he is out of sight, I cry the whole way home.*

*This is the first time I realize there are categories of “fat” and “skinny”. I am devastated to learn I am not in the “right” group. As the years progress, I grow to hate my body. I wish on birthday candles for weight loss and I pray to God for a smaller dress size. I attribute every failure and heartbreak to my body image.*

**Researcher-self:** Such blatantly direct bullying is like being shot at point-blank, with no place to escape. Fitting in is very important for school-aged children. Thus, not being “right” or “normal” often promotes feelings of loneliness, rejection, and a sense of abandonment. Being separated from others may often cause anxiety and fear.

**The school dance.** *My first school dance is the first time I remember feeling deep loneliness and self-hate.*

*“Let’s slow things down a little.” announces the DJ (disc jockey). The room splits in two, with girls on the right and boys on the left. As the music starts to play, the boys gravitate from the left to the right, pairing with the girls. I stand against the wall watching the pairs dance. The song is half way through before I realize I am alone. The feeling sinks deep. It starts as an ache in my chest, then radiates to my eyes to well up into tears. This is agony! Self-critical thoughts race through my mind, “You are too ugly to dance with! No one likes you! You will be alone forever!”*

**Researcher-self:** Where did this dialogue come from? I wonder if these thoughts echo criticism I heard from others. Or, is that what I believed people saw when they looked at me? At this stage of development young people often attribute their self-worth to their appearance, and peers’ comments are impactful. It appears as though I have become my own bully.

**Recess.**

*It is a beautiful summer day at school. I am laying on the grass with my two best friends. We watch the “popular” boys playing soccer as the “popular” girls march around the field in a group, like gossiping hens. We cannot help but laugh at this image. “I am so grateful to have you guys in my life. One day life will get better and none of this stuff will matter.” I say to my friends. They smile in agreement and we spend the rest of recess dreaming about our bright futures.*

**Researcher-self:** Even my friends and I felt somehow separated from the other students. I imagine we felt as though we could not compete with the “popular” kids. However, we felt a sense of comfort and belonging in our own group.

The word “bright” appears and I am reminded of my selected Lucida font to tell my stories. Despite many dark moments during my growing-up years, at some level, I still felt hopeful.

*During this time, despite the bullying, I feel strong and supported by my sister and my friends. I confide in them. I feel accepted, heard, and hopeful for a better future. However, it is hard to stay as close with them in high-school, as we attend campuses on opposite ends of the city. Even though the separation is not intentional, I feel abandoned throughout high-school, without my two best friends and without my sister.*

**Researcher-self:** Being separated from others, as human beings, we often experience anxiety and fear. I wonder why these common feelings led me to later exhibit behaviours of bulimia. Was it the accumulated combination of each lived experience that pushed me over the edge and towards illness? Was there no other way to keep myself safe?

### **The beginning of “it”**

I am not sure when I officially became aware of it...Recently I wrote the following poem...

**“It”**

*I don't remember when it all started.*

*All I know, is that my life would never be the same.*

*I consumed all my emotions, my dreams, my self-worth*

*I felt nauseous, anxious, reeling, retching, it was all too much*

*I purged all my fears, my pain, my doubt*

*I caved in, succumbed to my addiction, my affliction. (Aksenchuk, 2018)*

Here I think of J. K. Rowling's famous line “He who shall not be named”. The illness that is there, and yet, I fear to utter its name.

*I am 15 years old waiting in the doctor's office with my mother. I am overly aware of my thighs sinking into the soft chair. Oh God, why do they feel so heavy? I pinch my stomach, and I feel disgusted. I hate my body. I feel nauseous all the time. Months ago, I started vomiting almost once a week. Now, I vomit almost 6-7 times a day. I feel sad, exhausted and anxious. What's wrong with me? Am I sick? Do I have a horrible incurable disease? Will I need surgery? Will I need medication? I just want to be left alone!*

*A woman walks into the office. She does not introduce herself, but her scrubs suggest she may be a nurse. She talks to my mother, without acknowledging me. She weighs me and takes my vital signs. I respond by standing and walking to the large standing scale. The needle on the scale moves to the right and stalls on the estimated weight. My heart sinks... 0.2 lbs bigger than this morning, despite not eating all day. I am disappointed. Despite not wanting to be measured, I do not say anything. I try to be helpful and obedient. The nurse leaves.*

**Researcher-self:** I am sad for that young girl who is made invisible by the nurse.

Often, people who are bullied become obedient and fearful to offend others. What did I fear? If I was not nice or obedient, would others not like me? Did I equate approval with belonging and love? At some level, I just wanted to be accepted for myself. Maybe that is why I silenced and endured my disappointment and discomfort? Standing up for myself at that time would have been near impossible, with those heavy feelings and thoughts weighing me down.

*My family doctor enters and tells my mother I have something called Bulimia Nervosa. Bulimia? Like self-induced vomiting? I have never used my own fingers to induce vomiting! I vomit because of the anxiety and nausea I feel. No, I cannot have Bulimia...it must be a mistake. I am NOT crazy! There has to be*

*something physically wrong with me? An infection, a tumour, a hole somewhere causing all these symptoms. It cannot be all in my head!!*

**Researcher-self:** It is interesting that the first thought I associated with the diagnosis of Bulimia was “crazy”. Why did I make this connection? It appears as though a physical illness would have been more favorable and bearable, no matter how severe or life threatening. Why did I consider mental suffering outrageous? Do my mind, thoughts, and feelings define me? I value my intelligence, my sanity. Why was someone else’s labeling of me as “bulimic” suddenly become my accepted identity? I so quickly self-identified with this label and ruminated over what it meant to be known as such. I lost all sense of self. Being labeled “bulimic” made me feel like I would never be Sophia again.

*My mother jumps into problem solving mode. She starts discussing the research she found online and asks for referrals. Their voices turn into a distant roar in the background as I ruminate: How did this happen to me? Why did this happen to me? I do not have Bulimia! I do not want to be crazy! Why is no one asking me what I want? Is this not my body? Do I not get a say in this? Yet, I say nothing. I nod my head to signal I’m listening, despite thinking, “I am not crazy! I am not crazy! I am not crazy!!”*

**Researcher-self:** My mind appears to have broken away from my body. Separated from my body. My mind is the “self”. By labeling me bulimic, the “self” faded away and suddenly I had no control of my body. I became “it”, the Bulimia.

Being with my mother allowed me to take a back seat. I am labelled “sick” and my mother is “health”. I play the role of “ill person” and my mother plays the “healer”. Despite being at the developmental age where persons seek independence and solitude from family, I am in a position of dependence on my mother. I process my pain and illness, as she cares for me. Is

this paternalism? I am sure that other adolescents experiencing illness also rely on their parents for support. Recalling my nursing courses, illness is a trauma on the body, and so often we regress to earlier stages of our psychosocial development. How does this affect adolescent social development and identity formation?

### **The cycle of “it”**

“That’s the thing about pain...it demands to be felt” (John Green, 2012).

*“Drip, drip, drip” goes the leaky sink. “Ugh, make it stop” I groan. I cover my ears with my hands. I feel cold. I shiver, convulsing on the bathroom floor. I suddenly realize where I am. I suddenly realize where I do not want to be. Here. Here, on my bathroom floor. Again? I hate it here. Yet, here is where I have been for months now. How did I get here? Why did I come here? Yet, for some stupid reason, as I lay here on the bathroom floor, I still do not regret it, even after all the misery, conflict, and pain. Somehow, I think I deserved it. Deserve the punishment of almost destroying my own life, due to something that feels so out of my control. I feel like I cannot stop, as desperate as I may be.*

**Researcher-self:** Why do I think I deserve this “misery”, “conflict” and “pain”? What is preventing me from stopping? Is exhibiting this illness the only way I know how to survive ... how to call for help? Why is the idea of stopping these behaviours so threatening to me? What is bulimia helping me achieve? At this time, it appears to be the only way I have bared to tolerate my feelings and my life. The idea of stopping is so threatening. Of course, it is miserable; but it has become a large part of my identity and my way of being in the world.

*I find the strength to stand. I struggle to catch my balance as I reel. My stomach feels uncomfortably full. I stand on the scale and it reads 500 grams more than before my binge. I drink an entire bottle of water. I think about how*

*fat and disgusting I am. I think about how guilty I feel for eating. Suddenly, I feel nauseous. I bend over the toilet. The water feels heavy in my belly as I retch. As the content of my stomach begins to pour out of me, I feel better. I continue to water load and purge until my vomit looks cleared of food. I weigh myself and I am back to my pre-binge weight. I forgive myself. And suddenly, I feel hungry. I run to the kitchen. My mind takes a backseat. I have no control over anything. I feel numb. I stuff my face with anything I see in the fridge. I feel full of anxiety and guilt. I return to the bathroom to purge. I feel the anxiety slipping away as I crash from the high. The low lingers until the next binge.*

*Binging and purging is my life as a teenager. Nothing else matters. Not my family, not my health, not my friends, not my future. Nothing else matters! All I know and all I can do is binge and purge.*

**Researcher-self:** What was I avoiding by engaging in this behaviour? Perhaps it took the edge off facing reality. Stopping would mean I had to face real life, beyond the kitchen and the bathroom. Facing real life seemed worse than bulimia.

As I read and re-read this story, I feel the sudden urge to look up the word bulimia:

Greek *boulimia* ‘ravenous hunger,’ from *bous* ‘ox’ + *limos* ‘hunger.’

What was I hungry for? Perhaps, acknowledgement, love, understanding, and freedom.

Bulimia is more than a disorder. “It” is more than a mental illness. For me, “it” is a painful hunger for acceptance, life, and control. In the context of my life, “it” was (and in many ways still is) a complex and stigmatizing illness that caused me physical harm and emotional scars. My personal illness experience with bulimia is traumatic and unforgettable.

## Yet another hospital visit

*My mother and I wait in the Emergency Room (ER). I feel exhausted. Perhaps not sleeping for 3 nights has something to do with it. I fidget with my over-sized sweater. I feel for my ribs, counting from my breast to my belly and back again.*

*After several hours, we are transferred to the paediatric mental health unit. The nurse mispronounces my name numerous times, but I do not correct the nurse. I desperately want the nurse to help me.*

**Researcher-self:** Again, why am I trying so hard to be liked? Why do I care so much about how this stranger will react to me? The nurse is in a position of power. The nurse provides the help and I receive it. I want the nurse to like me, but in this case, I need the nurse to help me.

*A young doctor enters the exam room and I explain the misery I have felt for the past year. The young doctor promises to help me. I allow myself to feel hopeful and to explore a reality of being okay again. An older doctor enters the room. The older doctor does not introduce themselves. The older doctor's expression is cold, hard, indifferent. The older doctor does not say my name, nor does the older doctor ask to hear my story. The older doctor turns to my mother and tells her we can go home. My mom demands to know the rationale for this. The older doctor sighs and says "Your daughter is turning 18 this year, so she is too old for our program. Her labs and weight are not critical. She is not sick enough to admit. But come back if she gets worse. Otherwise, go to your family doctor". The older doctor leaves without addressing further questions.*

*My mind screams, "Am I not sick enough? Am I not worthy of getting treatment? Is my suffering not significant enough? "I feel pain and nausea. I have no voice. I swallow my pain. I leave home with shattered hope.*

**Researcher-self:** Care providers in uniforms accentuate the power differential between them and those receiving their knowledge and care. It was so important to me for these healthcare providers to validate my suffering. I wanted to be seen and believed.

*I feel pain and I know I am suffering; yet I allow myself to question my experience just because one doctor who spent two minutes with me, did not recognize my pain. Again, I keep my discomfort and pain to myself. I tolerate it! I tolerate the injustice and the rudeness of others. I take it in silence because I think I deserve it... I never question the superiors in my family. Thus, I never question or stand up to the perceived superiors in my life. This makes me feel weak and quiet when I should fight for my care and health.*

**Researcher-self:** This experience creates a contrast to the mischievous and adventurous child I once was. I lost who I was as a little girl. Illness stripped me away from me. Would I every be that person again?

### **Light in the darkness**

*It is a cold winter night. I feel palpitations. My hand gently strokes my protruding collar bone. I feel the strings of the prescribed Holter monitor attached to my chest. I am in an exam room with a psychiatrist in an ER, with my mother in the waiting room. This is the first time someone is speaking directly to me. It is the first time someone is really listening to me. Even though there is nothing the psychiatrist can do, they do not make me feel useless and unworthy as a person. The psychiatrist acknowledges that my suffering is real.*

*They sit quietly and do not interrupt me as I speak. For the first time [and unfortunately the only time], a healthcare provider does not try to “fix” me or insist they know what I am going through. The psychiatrist allows my reality to be my own. We speak for 4 hours straight. I feel grateful for being valued enough for the psychiatrist to share their time with me. I again return home, but somehow not as miserable.*

*Because of this doctor, I remain hopeful. I am inspired by the memory of this compassionate practitioner, when I enter my nursing program later, to become an empathetic, caring professional myself.*

**Researcher-self:** This appears to be one of the only person-centred interactions I have encountered in my search for healing. I am relieved and hopeful. Because of this person-centred approach, I perceived a future in which I am more than my illness.

### **The treatment**

*Eventually I start treatment as an outpatient at an acute care hospital. The treatment seems more cruel than the illness ...*

### *Uncertainty*

*I am not afraid to die*

*But I am afraid of being here*

*Afraid of them taking away the only control I have left*

*The only thing that makes me feel stable in life*

*I have no voice here*

*No sense of self*

*Some parts of the day I am not allowed to speak at all*

*Rules say no talking about food, bodies, anything that may “trigger”*

*But these are the very thoughts*

*That consume my mind*

*That prolong this illness*

*That give "it" power*

*I am silenced*

*Forced to endure my own thoughts*

*Alone*

*-and suddenly, as I realize this*

*I feel more alone than I ever imagined*

*Here, in this room, filled with people*

*I feel lost*

*I feel alone*

*I feel like running*

*A controlling, dominating voice screams out*

*You do not belong here,*

*you do not deserve to get better*

*You will not get better*

*You are....*

*Too fat*

*Too big*

*Too ugly*

*Too lost*

*Too crazy*

*...to be helped*

*I close my eyes*

*And pray the thoughts leave on their own*

*But they simply amplify in the darkness of my mind*

*As I smile to pretend everything is okay*

*Everything will be okay?*

*--won't it?*

(Aksenchuk, 2018)

*I sit at the table in my usual spot as the hospital staff serve the meal. The other eating disorder patients are seated at the table. The food on my plate does not look appetizing. I pick at it and debate whether I should eat it at all. Refusing to eat prolongs my escape from this place. And that possibility is worse than eating this slop. So, I shovel the slop into my mouth trying not to taste it, as I swallow large dry chunks of food. The hospital staff remind us, "That's just the disease talking, you must finish your plate".*

**Researcher-self:** To imagine a disease as a creature with human abilities [attributes], seems very silly to me. I believed my disease, like physical illness, is a part of me. "It" was my response to the natural tensions I felt as a teenager. It" was also a way of dealing with the trauma and suffering of my illness. I refuse to believe it was anything less than a part of my whole being. "It" could be quieted, but not separated. Maybe one day. But today, this is where I stand.

*The rest of my treatment is a foggy haze. I am followed to the bathroom up to an hour after every meal. The bathroom door has no lock and I am not allowed to flush until hospital staff check the toilet. I am constantly watched. I am consistently silenced. My behaviours are continuously monitored and controlled. No one asks why I exhibited eating disorder symptoms; hospital staff are more*

*concerned with stopping any behaviour they deem “abnormal”. I am not trusted to feel, think or be human, the only way I know how. I feel threatened as they try to strip away the only identity I have come to know: being sick. I feel uncomfortable and out of place almost every minute I am here, despite sharing this illness identity with other sufferers.*

*It all ends on a hot summer day. I am finally discharged... set free. I feel relieved and confused. My weight is “normal” and my pale skin has some colour to it. But the thoughts are still there. I learn to ignore them most of the time. But it takes a lot of hard work – relapsing, talking, yoga, sleepless nights, and countless self-help resources – before I finally know what to do with my thoughts. Still today, I do not always get it “right”, but that is okay. I work with it. I work at being gentle with myself.*

*I often say I am in “remission” of my illness, perhaps this is because I did not have the opportunity to fully process the illness. The treatment was very body and measurement focused. Out of fear of having to be in the hospital longer, I complied with the diet orders and suppression of my thoughts and behaviours so that I could be free again.*

**Researcher-self:** What actually counts as treatment ... full engagement or only robotic compliance? I believe them to be different. Engagement involves active participation and being allowed to fail; being honest with one’s self and being allowed to feel and think freely despite being bound in a hospital. I believe compliance is passive obedience, which involves no questions and no collaboration: receiving an order and blindly following it. Without full engagement, I am left with residual trauma, inevitable triggers, and never-ending pain.

## Getting by

*For a very long time, I felt terrified by the thought of people finding out I had an eating disorder. I see "it" as a permanent stain that I have to hide from the world. I fear that once the stain is visible for all to see, I am no longer viewed as a competent and successful person. I fear that the person I am will wash away and others will think I am weak and worthless.*

*For many years I thought, "No one can know, because no one will treat me the same; people will judge me; people will watch me when I eat; they will not understand me; they will not care to hear my story." These beliefs prevent me from sharing my stories. Today, I am a nurse on an acute care unit.*

*It's a warm fall day. One of my patients is a young person diagnosed with an eating disorder. I feel a flutter in my stomach as I read the report. I fear that if I react, people will know something is wrong and that I too may have had an eating disorder, so I say nothing as I prepare the morning medications.*

*During my care of this young patient, I make a conscious effort to speak with them directly. However, their family member answers every assessment question for them. My own memories flood in, as I witness this.*

*In the afternoon, I walk by the patient's room and notice they are crying alone. I sit next to the patient at their bedside. I listen (as the psychiatrist had for me so many years ago) and I do not try to discredit their reality. The patient asks me how I know so much about eating disorders. I do not answer. Part of me wants to share my story, the other part of me fears my coworkers would overhear me. The conversation ends. I leave the patient's room feeling disappointed, like I let them down. Part of me feels like I could have done more.*

*After my shift, I let myself cry, feeling that I am now part of this person's trauma.*

*My personal illness experience continues to be a significant part of my life today. Although, I carry the trauma and the experience with me, I am now able to step back and explore this aspect of my life through my Researcher-self, with compassion and increasing clarity of thought. This traumatic experience informs how I think, feel and act. I recognize when I feel safe, and when I feel my environment is triggering an unhealthy response. I use this knowledge to make healthy choices and venture on paths that serve my best interest, which includes compassionately caring for others in similar situations. I know what it is like to feel lonely, objectified, and controlled. With this expanding awareness and knowledge, I have the strength to advocate for myself and for anyone who has encountered stigmatizing illnesses.*

### **Looking back, Looking forward**

In the next chapter, I deepen my analysis through Practical Justification, where I access a theoretical lens and scholarly literature informed by emerging narrative threads in the stories of my illness experience.

## Chapter Six

### Practical Justifications

In this chapter, I continue to critically analyze the shared stories, thereby addressing the practical justification, the second level of analysis of Narrative Inquiry. Practical justification requires discerning “emerging narrative threads within and across the stories, which upon further reflection become visible as narrative patterns” (Lindsay & Schwind, 2016, p. 16). I identify a theoretical lens that best illuminates the inquiry puzzle. I also access the existing scholarly literature to make meaning of the emerging narrative patterns in order to further understand the shared stories within the professional context of nursing (Lindsay & Schwind, 2016).

At this stage of analysis, the voice of my researcher-self becomes dominant as I further explore and situate my stories of illness within the broader context of the nursing profession. I critically analyze the emerging narrative patterns by accessing further scholarly literature and expand my understanding of the told stories by using the theoretical lens of *Erikson’s Theory of Psychosocial Development* (Erikson, 1963; 1982).

### Theoretical Lens

In order to more fully understand the inquiry puzzle, how my personal illness experience as a youth impacts my professional self today as an adult, I use Erikson’s Theory of Psychosocial Development, also referred to as Erikson’s psychosocial stages (Erikson, 1963; 1982). I selected Erikson’s Theory of Psychosocial Development because, through this lens, I can explore how identity is formed personally and professionally within the social environment, and how these are mutually informative. This theory encompasses eight major *crises*, also known as psychosocial stages of development, throughout the life span that emerge at particular times through biological

maturation and social demands (Figure 1). I apply this theory to my personal lived experiences to display that even the most sequential and standardized theories within research and healthcare can be adapted to meet the needs of an individual. I believe that we do not need to feel stuck or labeled by any given stage but recognize that we are always flowing between the various tensions of psychosocial development observed naturally over time.

Stages	Age range	Psychosocial crisis
<b>Early Childhood</b>	1 to 3 years	Autonomy versus shame, doubt
<b>School Age</b>	6 to 12 years	Industry versus inferiority
<b>Adolescence</b>	12 to 20 years	Identity versus identity confusion

*Figure 1:* Adapted from Erikson’s (1982, pp. 32-33) stages of psychosocial development for the purposes of this self-study.

According to Erikson, in order to prepare for the next life crisis, the preceding crisis must be successfully resolved. The developmental stages most relevant to my analysis are the autonomy versus shame (age 1-3 years), industry versus inferiority (age 6-12 years), and the identity versus role confusion (age 12-20 years), as the lived and told stories predominantly take place during these periods of my life.

During the autonomy versus shame stage (age 1-3 years), children in early childhood must learn to be independent with their feeding, hygiene, and activities of daily living. Successful completion of this stage results in a sense of self-control and adequacy. Parents are the key social agents, otherwise the child will doubt their abilities and feel shameful (Erikson,

1963). It is important for young children to build trusting relationships with adult caregivers to support identity development (Green, Kalvaitis, & Worster, 2016). This stage is observed in my story entitled *Clear the plate*, where I discuss seeking independent play as a toddler.

During the industry versus inferiority stage (age 6-12 years), school age children compare themselves with their peers. They are tasked with mastering social and academic skills, and if industriously achieved they feel self-assured and competent. Teachers and peers are significant social agents in this stage. If the child fails to achieve these attributes, they feel a sense of inferiority and have difficulty learning and working (Erikson, 1963). This stage is observed in my stories *The bus ride*, *The school dance*, and *Recess*, all found within *The three epiphanies* section of my personal stories. In these stories, I share how I felt inferior to my peers as evidenced by bullying and exclusion.

Lastly, the identity versus role confusion (age 12-20 years), is a significant stage within my psychosocial development, as this is when the previous stages culminate in my experience of an eating disorder. Erikson (1963) noted that persons at this stage of psychosocial development are between childhood and maturity. The vital question facing the adolescent is “Who am I?” Both social and academic identities are established, otherwise the adolescent remains confused about who they are, often submerging their identity in relationships or group membership. This stage is reflected in the stories that speak of my illness experience: *The beginning of “it”*, *The cycle of it*, *Yet another hospital visit*, *Light in the darkness*, *The treatment*, and *Healing the wounds*.

I apply Erikson’s psychosocial development theoretical lens to critically analyze my stories through the three-dimensional space of temporally, socially, and through various places. Through this analysis, I gain a deeper understanding of how my personal experience of an eating

disorder during my teen years informs my professional self today. As I move backward and forward, as well as inward and outward, I continue to explore and understand the inquiry puzzle, while using the theoretical lens to address the practical justification level of analysis within context of the nursing profession.

In the following section, I explore the narrative threads that emerged from my stories, followed by the emergent narrative patterns. Narrative threads are the initial particular elements of the stories that emerge after reading and rereading the stories. Examining narrative threads is akin to closely examining the threads of a woven scarf to identify colour, texture, and thickness. In this way, narrative threads are intricate elements of the stories' embroidery. Through further reading and rereading, the threads become visible as narrative patterns. The narrative patterns become visible as broader elements of the story, similar to how the colours and textures in a scarf are mended together to illicit a particular image or design.

### **Narrative threads**

After reading and rereading my stories the narrative threads that came forward are lack of autonomy, lack of meaningful relationships, impulsivity as a response to losing control, and liminality. I critically reflect on each of these below.

#### **Lack of autonomy**

Autonomy is a state of independent, self-governed and self-directed decision making (Kayser, Cossette, & Alderson, 2014; Harnett & Greaney, 2008; Mullin, 2014). Erikson (1963) identified *will* as the strength to be developed in line with autonomy. Autonomy is developed by practicing a sense of self-agency, good will, and pride without loss of self-esteem. Self-agency refers to knowing self and own abilities as well as using these abilities freely as needed, without being controlled or oppressed by external persons. When a person losses self-agency and is

controlled by external forces, this leads to doubt and shame that ebbs and flows throughout the lifespan, if not addressed (Erikson, 1963; Graves & Larkin, 2006; Mullin, 2014).

According to Erikson's (1963) theory, during the second stage of psychosocial development, autonomy versus shame and doubt, toddlers begin to explore and move away from their caregiver's immediate environment. This is clearly displayed in the first story, *Clear the plate*, as I described my toddler-self as "...*very adventurous and mischievous...with an insatiable curiosity.*" However, my independent exploration was heavily guarded and discouraged by adult caregivers; "*the strong authorities that raise me demand respect and obedience. Eventually, as I grow, it wears me down*" (*Clear the plate*). Caregivers who hold on too close and prevent independent play create a restrictive or restraining pattern that can impede a child's ability to establish boundaries and safely test curiosity (Graves & Larkin, 2006; Joussemet, Landry, & Koestner, 2008; Mullin, 2014). My participant-self often refers to an external locus of control throughout my shared stories as the persons in my life are often making decisions for me. This is further explored within the pattern of control identified later in this section.

Once my independence was required later in my youth, such as entering high-school without my friends and my sister, I note that I begin to express unhealthy coping mechanisms, often characterized by impulsive tendencies manifested in my eating patterns. Since my adolescent experience with an eating disorder, I often felt that I lost my independence or lost my sense of self because of my illness, but, upon further reflection, perhaps I never developed autonomy. I did not feel "in control" of my own decision-making because I did not have my age-appropriate autonomy. I did not have my age-appropriate freedom to appropriately respond to

my psychosocial demands. Thus, my self-agency was thwarted by external controls from caregivers and cultural norms.

As I aged, lack of autonomous experiences led to a fear of being alone, as noted in the end of the *Three epiphanies*, resulting in poor identity formation and lack of self-advocacy. I allowed adults to speak for me, as reflected in *The beginning of “it”*. I struggled with my sense of autonomy within the healthcare system, as I doubted my suffering and my own feelings of despair. This in turn resulted in my further withdrawal to where I filtered what stories I shared with healthcare providers, as noted in *Yet another hospital visit*.

Within a healthcare lens, autonomy is an individual’s ability to direct their own care (Drake, Deegan, & Rapp, 2010; Lindberg, Fagerstrom, Sivberg, & Willman, 2014; Lynch, 2012). Issues with autonomy in healthcare stem from the perceived power the healthcare provider has over the patient with regards to medical knowledge and care delivery (Beauchamp & Childress, 2009; Lindberg et al., 2014). There is evidence to suggest fostering autonomy is particularly important among eating disorder patients, as autonomy leads to self-endorsed motivation that is internally controlled, rather than externally imposed change of disordered eating behaviours (Kayser et al., 2014; Ng et al., 2012).

Coercive language echoes throughout my stories, as I am told I *must* eat as a toddler by my grandfather (*Clear the plate*), and as an adolescent by hospital staff (*The treatment*). I felt “*continuously monitored and controlled*” (*The treatment*). However, this is not in alignment with the literature recommendations to promote patient autonomy in order to support positive health behaviour changes (Kayser et al., 2014; Lindberg et al., 2014; Lynch, 2012; Ng et al., 2012). Perhaps, that is why I struggled to self-manage once I was discharged from treatment, “*I complied with the diet orders and suppression of my thoughts and behaviours so that I*

*could be free again” (The treatment)*. I needed to find my own inner compass, and my own inner motivation and strength to make my own decisions.

### **Lack of meaningful relationships**

Upon reading and re-reading my stories of illness, there appears to be a significant lack of positive relationships and connections with peers. The story, *On the bus*, begins with an admission of recurrent bullying and describes a specific experience of being bullied by a classmate.

School bullying, also known as peer victimization or peer harassment, is defined as an imbalance of power with repeated physical, verbal, or psychological abuse intended to cause harm among peers (Graham, 2016; Olweus, 1993, 2013). During the industry versus inferiority stage of development, (6-12 years of age) if children are overly criticized and made to feel inadequate in relation to their peers or social norms, they develop a sense of inferiority (Erikson, 1968; Green et al., 2016).

Victims of school bullying often develop low self-esteem and loneliness (Juvonen & Graham, 2014). There is significant evidence demonstrating school-age bullying may lead to mental health problems later in development (Bayer et al., 2018; Bond et al., 2001; Carr-Gregg & Ramesh, 2011; Ford, King, Priest, & Kavanagh, 2017; Goncalves, Machado, Martins, & Machado, 2014; Nishina, Juvonen, & Witkow, 2005; Rugby, 2003; Thomas et al., 2017; Ttofi, Farrington, Losel, & Loeber, 2011; Undheim & Sund, 2010; Wade, Gillespie, & Martin, 2007). During adolescence, bullying appears to have a greater risk among girls than boys with regards to psychological well-being (Alivernini, Cavicchiolo, Manganelli, Chirico, & Lucidi, 2019; Chaplin & Aldao, 2013; Flook, 2011). Specifically, there is a significant relationship between earlier exposure to teasing specific to weight and size from peers and parents, with the

development of bulimia nervosa later on in life (Goncalves et al., 2014; Pike et al., 2006; Wade et al., 2007). This resonates with my story *On the bus* when a peer made a hurtful comment about my physical appearance, specifically using the word “fat”. As mentioned in the above evidence, there is support in believing my earlier exposure to teasing related to my weight and body image may have promoted my development of bulimia later on in life.

### **Impulsivity as a response to losing control**

Impulsivity appears throughout the stories in various degrees. Impulsivity refers to quick spontaneous reactions to internal or external stimuli without concern for the negative outcomes imposed on one’s self or others (Moeller et al., 2001). Feeling out of control with regards to eating was more often reported among persons with bulimia, as compared to persons with anorexia (Sassaroli et al., 2008), or those considered to be healthy (Budd, 2007). Feeding an impulse to binge or purge is considered a loss of self-control, which includes feeling shame for one’s lack of ability to independently approach problems in constructive ways, as young adulthood may require. This notion of being out of control is evident in the story *The cycle of “it”*, where I write about “losing control” of my symptoms, especially within a binge-and-purge cycle. I describe one of the cycles, “*my mind takes a backseat. I have no control over anything. I feel numb. I stuff my face with anything I see in the fridge. I feel full of anxiety and guilt. I return to the bathroom to purge*”. This feeling of impulsivity as a response to losing control, although frightening, gave me a false perception of control, which I desperately needed to feel in order to numb my feelings of anxiety.

### **Liminality**

The concept of liminality, what Erikson (1968) refers to as conquering dilemmas of the developmental stages, comes through my lived and told stories, specifically within the transitions

of major life events in my young life. These include transitioning between developmental stages, from early childhood to school age, and from school age to adolescence. In each transition, I carried the impact and/or trauma of the stage before it. In school age (*The three epiphanies*), I carried the consequences of not fulfilling my early childhood need for independent play and autonomous decision making. My lack of self-agency continued into school age, where I experienced bullying and lack of belonging. This in turn led to my adolescence, where I exhibited my first behaviours of disordered eating (*The beginning of "it"*).

Using Erikson's theoretical lens, I had not fully completed the requirements of the psychosocial changes throughout my early and later childhood. I entered adolescence with a sense of doubt and inferiority, not knowing who I am and where I belong. Liminality in this case refers to the "in-between states of indefinite temporality and undefined spatiality" (Eli, 2018, p. 476-477).

In the stories, there is a sense of being suspended in time, especially within the illness and treatment stories, as I enter the ambivalence between my healthy self and my ill self as an adolescent. Being ill altered the way in which I perceived, sensed, and related to others. I drew inward and away, developing "a liminal relational world, simultaneously embedded in and removed from bonds of sociality and kinship" (Eli, 2018, p. 483). The literature attributes these feelings of ambivalence, pause, and liminality to the disruption in one's life story and identity caused by illness (Bury, 1982; Charmaz, 1983), as well as the stigmatizing social position to which the person arrives (Frank, 1995). In "*The treatment*" story, I write, *I feel threatened as they try to strip away the only identity I have come to know: being sick. I feel uncomfortable and out of place almost every minute I am here, despite sharing this illness identity with other sufferers.* This became my way of being within the world.

The notion of liminality also holds an additional significance for me. I identify as a first-generation immigrant. I arrived in Canada with my family when I was only two years old. Although I grew up in Canada, I did so as an immigrant, the label I shared with my family. Identifying as an immigrant expresses my vulnerability as a new settler, never quite accepted in my new home and clinging to the mild comfort brought on by old traditions I learned from my family. In this space I experienced critical stressful life events unique to many immigrant children and adolescents: economic hardships and assimilation difficulties, often resulting in loneliness and alienation (Borraccino et al., 2018; Chuang & Moreno, 2011; Gualdi-Russo et al., 2014; Sookjung, 2018; Stefanek, Strohmeier, Fandrem, & Spiel, 2012). I struggled with situating my identity among my Canadian peers, while my family struggled to hold on to our cultural customs, as shown in *Clear the plate* where my grandparents took turns passing on cultural values. I revisit my experiences as an immigrant within the narrative pattern of belonging discussed in the following section.

### **Narrative patterns**

Through continued reading and re-reading of the stories and emergent narrative threads, and upon further reflection, the narrative threads coalesced and became visible as three key narrative patterns: *control*, *belonging*, and *identity*. In this section I analyze each pattern within the context of this study, with the intent to gain a deeper understanding how my personal illness experience with a food eating disorder during my youth informs who I am today as a professional, and specifically a nurse.

#### **Control**

The term *control* has an extensive theoretical tradition as an important construct in the development and maintenance of eating disorders (Bruch, 1973; Crisp, 1967, Fairburn, Cooper,

& Shafran, 2003; Garfinkel & Garner, 1982; Selvini-Palazzoli, 1974; Slade, 1982). Several studies have reported disorders, like bulimia nervosa, characterized by maladaptive behaviours and cycles of binge eating, as often being associated with impulsivity and impairments in inhibitory control; in other words feeling out of control (Budd, 2007; Claes, Nederkoorn, Vandereycken, Guerrieri, & Vertommen, 2006; Donovan & Penny, 2014; Jimenez-Murcia et al., 2015; Wu et al., 2013). In this study, based on the lived and told stories of my illness experience, I see control as a subjective perception of external and internal influences that suppress or direct certain behaviours (Sassaroli et al., 2008).

Locus of control is a term often associated with perception of power, as it refers to the perceived control a person has over their own lives (Mills, 1994). According to Mills, persons who attribute and identify an external locus of control are more vulnerable to disordered eating. Intrusive and controlling parenting is a common characteristic among families of patients with eating disorders (Enns, Cox, & Larsen, 2000; Polivy & Herman, 2002; Soenens et al., 2008). Moreover, persons who attribute or identify being controlled by guardians, specifically male family members, are more likely to exhibit symptoms of bulimia and poor self-esteem, as compared to healthy control groups (Rorty, Yager, Rossotto, & Buckwalter, 2000; Sassaroli et al., 2008; Soenens et al., 2008).

Throughout the narrative, I refer to the need to control my thoughts and emotions, which are described in literature as behaviours characterizing bulimia nervosa. For example, in *The cycle of "it"* I share "*I feel full of anxiety and guilt. I return to the bathroom to purge. I feel the anxiety slipping away as I crash from the high. The low lingers until the next binge.*" Within the literature, it is reported that when persons with eating disorders enter a state of rumination and worry, they show an increased desire to control their emotions and feelings.

This in turn leads to an increase in bingeing and purging to cope with dysphoria and to modulate their mood (Laghi, Bianchi, Pompili, Lonigro, & Baiocco, 2018; Olstad, Solem, Hjemdal, & Hagen, 2015). This resonates closely with my understanding of bingeing and purging, as it was my way to be within the world, while dealing with my expressed anxiety and rumination.

Alternatively, developing a rigid focus on eating and thinness is associated with maladaptive perfectionism in which such behaviour is used to compensate for a perceived lack of competence and control persons experience in life (Flett, Hewitt, Oliver, & MacDonald, 2002; Shafran, Cooper, & Fairburn, 2002; Soenens et al., 2008). The personal drive for meeting the standards and “orders” of the world around me may have promoted escalating patterns of disordered eating behaviours. I desperately wanted to be myself, even though it was different from my family of origin, and perhaps not quite the same as that of my peers. I just wanted to be accepted as me.

## **Belonging**

Lack of *belonging* is exhibited by feelings of loneliness and absence of meaningful relationships. Within this analysis, I explore the pattern of belonging by examining the impact of relationships and social connections throughout my lived and told stories.

Erikson (1963) noted that adolescents often submerge their identity in relationships or group memberships when they are not able to successfully define who they are as individuals. In my stories I note a sense of abandonment when I am separated from my sister and friends. I felt isolated and lost navigating the spaces of adolescence alone. I did not seem to have a sense of belonging to any particular group.

I experienced displacement at an early development stage when I immigrated to Canada as a toddler. The parental figures in my life reinforced the values and customs of our eastern

European culture in various ways. The most significant means of reinforcing the culture of my birthplace occurred throughout my attendance at an eastern European Catholic elementary school. Despite my knowledge of cultural norms, I did not find my sense of belonging there. As an adolescent, I was lost in a public-school mosaic of cultures. Despite everyone's differences, I did not find my belonging there either. I experienced bullying and isolation throughout my school journey, akin to the unfortunate common occurrence for many immigrant adolescents (Alivernini et al., 2019; Alivernini & Manganelli, 2016; Alivernini et al., 2017; Borraccino et al., 2018; Strohmeier, Karna, & Salmivalli, 2011; Vitoroulis & Georgiades, 2017).

I was a small child when I arrived in Canada and I identify myself as a first-generation immigrant. According to the literature, first-generation immigrants report higher incidents of bullying than second generation immigrants, those who were born in the country they live in, but whose parents were born in another country (Borraccino et al., 2018; Vitoroulis & Georgiades, 2017). Adolescent immigrants have the highest risk for reporting health concerns, loneliness, low life satisfaction, and episodes of bullying (Borraccino et al., 2018; Chuang & Moreno, 2011; Holmberg & Hellberg, 2007). Immigrant adolescents in Canada experience increased occurrences of body dissatisfaction, specifically dissatisfaction with body image and appearance (Kimber, Georgiades, Jack, Couturier, & Wahoush, 2015; Magtoto, Cox, & Saewyc, 2013). Body dissatisfaction is a risk factor in the development of eating disorders (Stice, Marti, & Durant, 2011; Stice & Shaw, 2002). Thus, my unique position as an immigrant in Canada may have supported my eating disorder identity as an adolescent.

As my stories suggest, I became more aware of my isolation: my age progressed but my identity somehow became lost and undeveloped. However, I found temporary comfort in belonging to the group of persons with eating disorders. Any attempt at removing myself from

this group, especially in treatment, seemed like a threat to my sense of who I thought I was. This notion of not belonging is closely tied to my sense of identity, which I discuss under the pattern of identity in the next section.

Anthropologists have suggested that eating disorders are highly relational experiences, involving elements of social boundaries and the renegotiation of relationships when the person becomes ill (Lester, 1995; Warin, 2010). There is an association between belonging and control. Budd (2007) observed that disordered eating behaviours occurred as a method of control among women who lacked connections and close relationships with others. Optimistically, when meaningful relationships presented in their lives, the maladaptive coping and disordered eating significantly decreased (Budd, 2007).

My disordered eating behaviours progressed throughout adolescence as a means to cope with loneliness and isolation, which was further imposed by the illness intended to mediate these emotions. Unfortunately, it appears creating meaningful relationships continues to be challenging. I find it difficult to share my experiences of eating disorders with others, for fear of being shunned by anyone who hears my stories. This is especially so in my professional role. This fear of judgment and stigmatization sustained my silence and isolation into adulthood (*“Getting by”*). Engaging in this self-study is my attempt to break this silence to not only gain a deeper understanding of my socially stigmatizing illness, but in hopes to inspire courage in others, who may be in similar situations, to find their own voice out of the lonely silence.

## **Identity**

Identity is defined as an “individual’s perceptions of their characteristics and abilities, their beliefs and values, their relations with others, and how their lives fit into the world around them.” (Erikson, 1982, p. 471)

Identity is a substantial pattern throughout the stories, particularly in the personal illness experience within the last six stories, *The beginning of “it”*, *The cycle of it*, *Yet another hospital visit*, *Light in the darkness*, *The treatment*, and *Healing the wounds*. Adolescence is a vulnerable time in the life span, where persons aged 12 to 20 years are tasked with exploring and committing to an identity, as they emerge into adulthood (Erikson, 1963; 1982). This is a crucial period for identity development, as adolescents establish a clear and definite sense of who they are and how they fit into the world around them. Identity development requires reflecting on the traits, abilities, and interests, trying out various possibilities and ultimately making commitments with identities formed in personal relationships, work, and ideologies. Failure to establish a stable and secure identity results in identity confusion (Erikson, 1963; 1982).

Successful completion of this stage provides a stable foundation for later development in adult life. In the story *“Getting by”* there is notable trauma, as I tell of my fear of being stigmatized if I fully disclosed my experience of an eating disorder with a patient in a similar situation. As the story details, out of fear, I chose not to share my own story to the patient. I cried once the interaction was over. I think I cried for both, my own fear and for the young patient dealing with “it”. This described encounter demonstrates my own struggle, an uncertainty with knowing who I am and what my role is in relation to the patient, as well as returning fear of being bullied again by my peers, even though I am now an adult and a professional.

Professionals often fear sharing their mental health experiences in the workplace due to stigma (Baldrige & Viega, 2006; Baldrige & Swift, 2013; Moffitt, Bostock, & Cave, 2014; Price, Salzer, O’Shea, & Kerschbaum, 2017). Despite this knowing, I still wonder if sharing my story weakens my identity as a practitioner. I appear to be lost along the spectrum between patient and health care provider, never fully reaching either end. I grasp for the comfort of the

dominant identity I had as an adolescent entitled “patient”, which no longer applies, as I am mostly recovered, and my new professional role of “nurse”, which somehow feels inadequate as I hide behind fear of sharing my stories of my lived experience of eating disorders. Am I an immigrant again, in that liminal space? I am no longer in my birth-country, and yet I do not fully identify with my adopted one.

Eating disorder sufferers often welcome the title of *an eating disorder patient* as it embodies a way of being within the world (Eli, 2014; Warin, 2010). *Patienthood* shaped my eating disorder identity, as treatment required being entangled in the disconnected and objectified biomedical idioms. However, I did find a sense of personhood and hope when I spoke with a doctor who saw me as a human being and allowed me to share my story with them (*Light in the darkness*). The psychiatrist listened, and I felt heard and seen for who I am. Sharing personal stories is a means of maintaining a sense of self and personhood, while experiencing mental illness (Baldwin, 2005). Despite not knowing who I was beyond my illness, this humane invitation by the doctor (*Light in the darkness*) to share my story and to be heard, created space for me to recognize myself as a whole person, extending beyond my illness.

### **So, how does all this matter?**

I did not successfully conquer the adolescent psychosocial stage of development, as I was not able to establish a consistent identity having jumped from ill-person to patient to remitted bulimic. I wore these labels because I did not know who I was beyond them. In adulthood, I hid behind these labels to wear the mask of my perception of a professional nurse – cold, impersonal, and task-oriented. I got the job done, to only further roam the liminal space of not knowing who I truly am. I am still uncertain of who I am, but I am more accepting of this uncertainty. Sharing my stories helps break through the shame I feel by knowing I am not alone. Now, I am at a place

where I can explore who I am and I can identify with my past, present and future as a whole rather than as scattered fragments I pick and choose to display to the outside world.

I recognize that I have experienced a socially stigmatizing personal illness as an adolescent. Fear of being stigmatized and thus socially rejected, prevented me from disclosing my illness story to others, which stifled my personal growth and my professional practice. As a result, I have not been able to fully and wholeheartedly engage in my role as a nurse. My authenticity is jeopardized each time I stop myself from entering the vulnerable depths of sharing my stories with another person (*Getting by*). Sharing stories is something that seems so natural to humans. However, experiencing a stigmatizing illness is grounded in fear secondary to anticipated judgment, bullying, and losing one's sense of self, including one's professional credibility. By sharing my personal illness stories in this thesis, I hope to illuminate the truth behind experiencing a stigmatizing illness and inspire other to come out from the shadows of fear and shame.

Telling my stories of illness, deconstructing them, and analyzing them using Erikson's theoretical lens, enlightened by other scholarly literature, I have come to appreciate the value of my experiences. Through telling my stories, I hope to accept who I am as an adult person and a professional. I also hope to inspire others to tell their own stories, for their own healing and acceptance, and to thereby decrease the societal stigma of eating disorders.

### **Looking back, Looking forward**

In this chapter, I shared how my personal illness experience affected a crucial milestone in my psychosocial development during adolescence, identity development. My inquiry puzzle, *how does my personal illness experience inform my personal and professional identity*, is illuminated as I explore the emergent narrative threads and narrative patterns. I carried the

unresolved conflicts of prior psychosocial stages into adolescence, including shame and doubt from early childhood, and inferiority from school age. These conflicts emerged as narrative threads to be explored within and throughout the stories, including lack of autonomy, lack of meaningful relationships, impulsivity as a response to losing control, and liminality. I compensated for my perceived lack of control and belonging by grasping the identity of ill-person and patient. I identified with my eating disorder. But that identity was stripped away through treatment, I felt insecure in my identity as an adult who is also a nurse (*Healing the wounds*). As a professional, I feared the stigma associated with disclosing my eating disorder. However, through exploring this inquiry puzzle in form of a self-study, I have come to appreciate how sharing a personal illness experience can serve a greater purpose to humanity. In the following section, entitled Social Justification, I explore the potential significance of my work to society at large, and consider the potential contributions my study may have to nursing practice, education and research.

## Chapter Seven

### Social Justification Chapter

The practical justification stage of analysis is followed by the social justification. Social justification is the global perspective of the inquiry and its “impact on social environment” (Lindsay & Schwind, 2016, p. 16). In this level of analysis, I “delve deeper into research literature that expands beyond the nursing profession and interrogate the purpose of the inquiry puzzle” (Lindsay & Schwind, 2016, p. 16). I ask and attempt to respond to questions, *What lessons does the inquiry offer, and to whom? In what context would this be useful?* I address how the “gained insight about the investigated phenomenon contributes to the expansion of interprofessional and interdisciplinary knowledge” (Lindsay & Schwind, 2016, p. 16). In this chapter, I explore the possible implications this study has for practice, education and research.

### Practice

In consideration of the impact on practice, I will specifically focus on nursing practice within the broader group of healthcare providers, who are also invited to consider these possible benefits within their specific professions. The impact of this study is not limited to mental health nursing practice, despite the greatest relevance may come through in mental health. I recognize the growing need for mental health competence across various units and healthcare settings as persons may exhibit signs and symptoms of mental illness at any time when accessing the healthcare system. However, the essence and nature of Narrative Inquiry is an invitational quality. This means my self-study may contribute to the development of mental health knowledge. However, its greatest contribution is inviting other healthcare providers to enter their own inquiries regarding care for persons with eating disorders or their own personal experience of a stigmatizing illness. I believe this invitational quality may impact professional practice in

two key ways, through person-centred care and relational practice, and potentially contribute to mental health practice.

### **Person-centred care**

Person-centred care refers to providing care to persons with unique beliefs and values and tailoring care delivery to meet the person's unique health, social and cultural needs (Betancourt, Green, Carrillo, 2002; Ekman et al., 2011; Fredericks et al., 2012; Kolapo, 2017). Person-centred care improves health outcomes and patient satisfaction (Ekman et al., 2011). However, it is often difficult to implement in practice. Person-centred care involves expressing cultural sensitivity to respect a person's social position and cultural identity (Kolapo, 2017). As mentioned, I identify myself as a female first-generational immigrant. By exploring and sharing how this identity presents itself within and throughout my personal illness stories, I exemplify the need to explore such identities with patients as key elements in their lived illness experiences. Throughout the years, it has been difficult to define and implement cultural awareness in healthcare practice (Boyle & Springer, 2001; Hayes-Bautista, 2003; Suarez-Balcazar et al., 2011). However, reading, sharing, and exploring personal illness stories, as those presented in this thesis, could help to promote person-centred care and shine a light on the sociocultural identities that may affect a person throughout their illness experience.

### **Relational practice**

Relational practice involves recognizing that each person "has a unique, personal, socio-historical location that shapes a person's identity, experience, interpretations, and ways of being in the world" (Doane & Varcoe, 2015; p. 15). To share lived experiences with patients involves entering a space of dialogue and collaboration that cultivates trust, therapeutic communication,

and empathy (Doane & Brown, 2007, 2011; Schwind, 2014). In this way, nurses and patients engage in a therapeutic relationship where they co-construct patient's illness experience, creating a greater potential for meaning-making. Doane and Varcoe (2015) identify five relational capacities (*commitment, curiosity, compassion, competence, and corresponding*) that support this mutually respectful and potentially healing therapeutic relationship. In this light, my study has the potential to encourage nurses to develop these relational capacities by entering into their own inquiries, of significance to them, lived experiences. And, upon this process of critical reflection, to appropriately share of themselves to support persons in their care.

### **Mental health practice**

Although it was not my intention at the outset of this self-study to critique current mental health practice with respect to eating disorder treatment, I now realize that my work may indirectly inform the need for its transformation. Throughout my personal illness stories, I touch upon the various traumas I endured in illness and its treatment. This draws special attention to recognizing and hearing patients' stories as experts in their own lived illnesses. Mental healthcare providers may benefit from the use of sharing and hearing stories of personal illness in order to amend, develop, and reinforce practice standards that would more fully support person-centred care.

### **Education**

My inquiry puzzle, *how does my personal illness experience with an eating disorder impact my personal and professional identity*, required a shift from seeking knowledge, to consciously being within a space of exploration and wonder as a learner. There is no answer key or final chapter to consume in order to mark the end of this knowledge, rather to share a personal story of illness that continuously evolves with new patterns and threads emerging depending on

which lens is applied. In this way, education and learning is relational, as stories are lived and told through authentic engagement with the self and others (Schwind et al., 2014).

In the inquiry puzzle, I question how personal illness impacts my personal identity as well as my professional identity. With regards to obtaining or promoting knowledge development, this study may serve education through promoting personal knowing (Carper, 1978; Chinn & Kramer, 2015). This study may encourage others to engage in reflection and sharing of lived experiences, which are known to increase self-awareness and self-knowledge. Ultimately this study highlights that through seeking and building one's knowledge of self they inform their knowledge of who they are as professionals (Schwind et al., 2011).

Another way this study may contribute to the development of nursing knowledge is cultivating relational practice among nursing students. Unfortunately, relational caring practice is difficult to foster in nursing education and academia (Spandoni, Doane, Sevean, & Poole, 2015), as most curricula are focused on knowledge of theory and content. However, nursing knowledge and practice require a focus on experience, action and people. Thus, it is vital to create opportunities to share and reflect on experiences and development of personal knowing (Doane & Brown, 2011). Sharing stories of lived experiences creates opportunities for learners to engage with others in a humanistic way and to foster their relational capacities (Doane, 2002; Doane & Varcoe, 2005). Through this study, I hope to invite readers to enter their own inquiry, as well as to share stories of lived experiences with others, so that each of us can be seen and heard. Giving voice to stigmatized illnesses brings them out of the shadows, and allows the nursing profession, as well as the society at large to normalize these traumatic events.

## **Research**

As mentioned earlier, Narrative Inquiry has an invitational quality. Thus, I hope my study inspires others to explore stories of personal illness, especially stigmatizing illnesses. Specifically, my study may motivate and encourage other healthcare providers and researchers to break through their fear of disclosure and share their personal illness stories. This sharing would then build the current body of literature and qualitative research that could help healthcare providers and readers appreciate the trauma associated with the experience of a stigmatizing illness.

### **Looking back, Looking forward**

In this chapter, I considered the possible contribution of my Narrative Inquiry self-study to practice, education and research in the context of the broader society. In the following chapter, I share a re-presentation of what I have learned from critical analysis of my illness experience as an adolescent.

## Chapter Eight

### Re-presentation

In this chapter, I re-present my illness, a reconstructed story, in the form of a letter addressed to a young person who may be now struggling with a stigmatizing illness. In this reconstructed story I express what I have learned through the critical analysis of my experience with an eating disorder during my adolescence.

Dear Young Person,

I would like to share with you what I have learned from my experience with an eating disorder during my adolescence. Perhaps you are in a stage of development right now, where you are figuring out who you are. Maybe you are struggling with this stage of your life or perhaps with a stigmatizing illness of your own, or both. I hope my poetic prose inspires you, whenever you are ready, to courageously and authentically question and share your own story.

My poetic prose is entitled *Conquer from within*. This implies that our greatest battle in life is with our selves. My experience with an eating disorder during adolescence and my inquiry into who I am as an adult and a professional was a personal challenge of overcoming my own fears, pain, and trauma. Thus, my greatest lesson and advice from this experience is to conquer with kindness and gentleness from within, every day.

#### *Conquer from within*

*Like most diary entries, letters, and essays, I do not know where to begin. But here we are...past, present, and future seem to be one.*

*I look back at all the pain. All the pain that seems so distant, yet the scars still hold strong. A patchwork of memories that blend with my tattoos, a permanent memory. The numbness once so strong is now a state of limbo we live in. Who am I?*

*I am the little girl that grew up wanting nothing more than freedom and acceptance.*

*The little girl who had hope,*

*Who hid her pain,*

*Who never spoke ill of her family, despite all that she had seen*

*I am the young girl that felt like she never belonged.*

*The young girl who yearned for a friend,*

*a recess without tears, and*

*a partner to dance with.*

*I am the adolescent who did not fit in,*

*who hated her skin,*

*who never forgave herself for eating*

*I am the label the hospital placed on the file that belonged to me,*

*a person with a heart, a mind, a soul, and a dream.*

*I am the tests they conducted on the body that belonged to me,*

*a person who is someone's daughter, sister and friend*

*I am the weight, height, blood pressure, and electrolytes they measured that belonged to me,*

*a person who will one day work alongside them in the hospital*

*But...who am I, really?*

*Can I really be an adult, if I never conquered toddlerhood, childhood, and adolescence?*

*Can I really be a healer, if I was ill?*

*Can I really be a competent nurse, if I still wear the scars of my illness?*

*I am the stories I live and share. I am my past, present and future.*

*I am a wounded healer trapped in fear, yearning for acceptance and approval.*

*I belong to a growing community of people-with-stories.*

*People who live stories of illness, stigma, and fear.*

*We walk the earth wondering if we suffer alone. Isolated in our inside world of torment. Not sharing our stories is by far the greatest loneliness we will ever feel.*

*I walked alone for many years. I hid the pain. I hid the scars. I hid my stories. I hid who I really was,*

*because I did not know how to harmoniously be my past, present, and future.*

*I did not know how to be someone who experienced a stigmatizing illness, who is also a healthcare provider, and who is also a person worthy of love, belonging, and agency.*

*I felt trapped by my own fears of what might be.*

*Today, I conquer from within. I am no longer afraid and ashamed. I share my stories, so that we may share our stories.*

*Today, I am my past, present and future. I am hopeful looking at tomorrow.*

*I want to wear my wounds and scars, just as they are. No more, no less.*

*I am finding healthy ways to live with authenticity, empathy, compassion, and acceptance.*

*If you had similar experiences, please join me in sharing our stories; together we become stronger and healthier*

*So that humanity around us can learn to open its heart and let us in.*

In solidarity,

Sophia Aksenchuk

## Epilogue

### *Cliff jumping*

*I am on the edge of a cliff.*

*I feel the cold rock beneath my feet. I feel fear.*

*I feel free.*

*Despite the obvious danger, I want to jump.*

*I am not scared of dying. I am scared of failing, of being raw, naked,  
surviving the danger only to find myself paralyzed. No longer able-bodied.*

*No longer fully alive.*

*I boarder on extremes. I want to die or live. There is no in-between.*

*I look down to see the water at the end. I have been planning this jump for a while.*

*Years of planning, imagining what it would be like once I land in the water.*

*What would people think? Would they be proud? Would they think I am stupid for making  
the jump? Would they admire me? Would they want to jump themselves?*

*I close my eyes and block out the thoughts. I take a deep breath and dwell in the comfort of how  
safe it feels to be here at the top, where no one has seen me jump. Where no one can see that I  
am scared.*

*I challenge the fear as I remember why I want to do this. For me.*

*For others who fear what I fear.*

*For the world to know it is okay to fear.*

*I lift off the rock with my toes pointed down to the water, there is no looking back. I let out a big  
scream as I plunge into the refreshing water.*

*There is no looking back now. I have made a splash. I am alive once again!*

This journey has felt like a giant leap of faith. I never imagined sharing my personal illness stories in this way. I have gone cliff-jumping before, and a lot of the same feelings I feel while jumping off a cliff I felt during this inquiry process. However, just as cliff-jumping is recreational, I must admit part of this thesis journey was exhilarating and fun. Exploring a personal illness is a scary, exciting, and thrilling adventure. It exposes raw vulnerability, uncertainty, and angst that one never expects to expose. But like cliff-jumping, there is an art in this exploration of personal knowledge gained through lived stigmatized experience, coupled with scholarly work of others. I am grateful for my guide, who helped me navigate the nuanced steps and mis-steps, the challenges and the joys in this, at times frightening, and rewarding journey. I have arrived, looking forward to new adventures ...

## Appendix A

Research Ethics Board exception from review: Emailed letter



Sophia Aksenchuk <sophia.aksenchuk@ryerson.ca>

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### Ethics Application - No REB Review Required

1 message

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rebchair@ryerson.ca <rebchair@ryerson.ca>

Mon, Jun 11, 2018 at 5:11 PM

To: sophia.aksenchuk@ryerson.ca, jschwind@ryerson.ca

Re: REB 2018-244 Personal Illness Experience of my adolescent self: An Arts-Informed Narrative Inquiry.

Dear Sophia Lisak,

The Research Ethics Board has determined that your protocol does not require its review.

Thank you for your application for ethics review for the above noted study. Based on the information provided in your application, it seems that this project is more of a self-reflection piece (than, per se, autoethnographic) and outlined that no specific stories would be shared, rather it would be a project in which you would reflect, quite generally, on your own work experiences, as described. As a result of much more emphasis on the reflective aspect of the study, rather than the descriptive element, we deemed it not to require review. Should your proposed methodology change, please reapply to the REB for ethics review and approval. Good luck with the project.

If you have any questions regarding your submission or the review process, please do not hesitate to get in touch with the Research Ethics Board (contact information below).

Record respecting or associated with a research ethics application submitted to Ryerson University.

NOTE: This email account ([rebchair@ryerson.ca](mailto:rebchair@ryerson.ca)) is monitored by multiple individuals. If you wish to contact a specific member of the Research Ethics Board, please do so directly.

Yours sincerely,

Dr. Patrizia Albanese, PhD  
Chair, Ryerson University Research Ethics Board  
(416)979-5000 ext. 6526  
[palbanes@soc.ryerson.ca](mailto:palbanes@soc.ryerson.ca)  
[rebchair@ryerson.ca](mailto:rebchair@ryerson.ca)

<http://www.ryerson.ca/research>

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Dr. Asher Alkoby, LL.B., PhD  
Vice-Chair, Ryerson Research Ethics Board  
(416)979-5000 ext. 2491  
[aalkoby@ryerson.ca](mailto:aalkoby@ryerson.ca)  
<http://www.ryerson.ca/research>

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Toni Fletcher, MA  
Research Ethics Co-Ordinator  
(416)979-5000 ext. 7112  
[toni.fletcher@ryerson.ca](mailto:toni.fletcher@ryerson.ca)

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Zakiya Atcha, MSW  
Research Ethics Co-Ordinator  
(416)979-5000 ext. 4841  
[zakiya.atcha@ryerson.ca](mailto:zakiya.atcha@ryerson.ca)

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