

Exploring Disordered Eating and Chronic Illness: A Journey of Recovery Through OSFED
by

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Abstract

Research identifies eating disorders as a biopsychosocial with the highest mortality rate of all psychiatric illnesses. Using the process of autoethnography, my personal experience recovering from OSFED with a chronic illness is compared with current literature on the subject to explore some of the barriers to recognition, access to treatment, and recovery to eating disorders.

Exploration of the interconnectedness and additional challenges inherent in balancing a chronic illness and disordered eating from the perspective of the chronic illness as a predisposing factor.

This research also identifies and explores the relationship between disordered eating and culture.

Enhancing education and understanding of the nuances associated with eating disorders, both within professional and personal communities, may help to alleviate barriers to treatment and address issues related to stigma that exacerbate the challenges of recovery.

Keywords: OSFED, Chronic Illness, Autoethnography

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Dedication

For my daughter; the light of my soul.

May you have the confidence to compassionately embrace who you are, and the courage to ambitiously pursue your goals and dreams.

Exploring the complexities of OSFED and chronic illness

Chapter 1: Introduction

Introduction

Complexities associated with eating disorders of all categories make them one of the most difficult psychological disorders to treat, sustaining one the highest mortality rates of all psychologically diagnosable conditions (Sharan & Sundar, 2015). They infect the psychosocial emotional lives of those living with them; left untreated, eating disorders typically evolve in ways that negatively impact physical health. Each person's experience with disordered eating is complex and unique making prevention, identification, assessment, diagnosis, and treatment extremely challenging for practitioners and clients alike. To date, no treatment approach for eating disorders is regarded as superior to another (Lynch et al., 2013); however, there is agreement in research literature for the importance of adopting multidisciplinary approaches to address their multifactorial origin, resulting in medical complications (Holmes, 2017; Rowe, 2017; Sharan & Sundar, 2015)

ED¹ Arises

Anger, frustration, helplessness, hopelessness, insecurity, and defeat crush my soul. ED yells, *you're so stupid! You're fat! Of course, no one could love you, you screwed up, it's all your fault!* My heart is suffocating, my body is enveloped with anguish, and my brain can't handle the pressure. ED screams with a piecing, overpowering voice, *it's stupid to feel sad, crying is weak, you're dumb to feel hurt, suck it up! pinch, scratch, hurt, pain.* I can't handle the emotions, the

¹ ED is the personified voice inside me that encourages maladaptive behaviours and intrusive self-harming thoughts intertwined in a relationship with my eating disorder. The concept of ED was founded in "Life Without Ed" (Schaefer, 2014).

distress it causes, and the pressure any longer. All my energy has been spent resisting self-hatred and self-harm. I don't have any more strength left to resist ED and forfeit. Instantly I feel the pressure subside. The hurt, defeat, and self-loathing are there, but it is quiet and settled at the bottom of my soul.

Upon reflection of my life, I realize that ED always had a presence inside me. ED was disguised as insecurities I experienced throughout my life, that gained power and presence as the increase in pressures of life arose. ED used to be the whispered voice inside that told me all the bad aspects and events of my life were my fault; that to feel good, I needed to ignore the "bad" emotions, and that what others thought of me was much more important than what I thought of myself. In the dissolution of my marriage, ED's presence in my thoughts and feelings about myself gained power. In the following years, ED picked up traction and infiltrated my life until I could no longer deceive myself from ED. ED impressed upon me the emotional relief, I would feel in losing weight, self-harming, becoming perfectionistic, and controlling everything in my life; he was right. Whenever I became overwhelmed with the stresses of life or experienced unwanted emotions, ED was extremely effective in calming the chaos.

Background to the Problem

Eating disorders present a significant social issue to societies around the world and more so in westernized countries where socio-cultural beauty pertaining to women, is defined by "thinness," which is a risk factor for the development of anorexia nervosa (Peat, Peyerl, & Muehlenkamp, 2008). Their statistics display the highest mortality rate among any other psychiatric illness and are characterized by high levels of chronicity and relapse (Dingemans et al., 2016). The complexity of attributes associated with eating disorders pose challenges for assessment, diagnosis, and treatment. Research on eating disorders indicates that the prevalence

of Other Specified Feeding and Eating Disorder (OSFED), is higher than any other eating disorder category (Lahteenmaki et al., 2014; Dakanalis et al., 2017). Research by Fairweather-Schmidt (2014), indicates that, despite OSFED regarded as a subthreshold category of disordered eating, it maintains that similar rates of impairments to threshold eating disorders. In general, public lack of education, misinformation, and deficient understanding often trivializes the severity of eating disorders, adding barriers to accessing treatment (Dimitropoulos, Freeman, Muskat, Domingo, & McCallum, 2016).

Purpose of the Study

The purpose of this autoethnography is to explore my experience living with OSFED and a chronic illness that added unique elements to its trajectory, contributing research in this area, where information and studies in this area are scarce and less understood. I will also engage in exploring the interconnectedness of experiencing emotions, distress, perfectionism, and control in disordered eating behaviours. Furthermore, I investigate the significance of learning about emotional regulation, distress tolerance, and mindfulness through Dialectical Behaviour Therapy and individual therapy in my recovery journey. Drawing from my personal experiences, I will engage in discussion of systemic and cultural barriers to identification and acceptance, treatment, and the process of recovery while attending to aspects that may be unique to OSFED. The process and product of this paper is intended to increase the author's understanding of the development and trajectory of their eating disorder. Secondly, this research seeks to contribute to researchers, doctors, counsellors, and public knowledge to facilitate better understanding of the unique challenges and complications inherent in eating disorder. I hope this research provides insight that will aid in prevention, assessment, and treatment of individuals afflicted with eating disorders.

Definition of Terms

Subthreshold. As it pertains to diagnosis of eating disorders, subthreshold represents the categories classified as Other Specified/Unspecified Feeding and Eating Disorder, which do not meet full diagnostic criteria for the threshold diagnosis of Anorexia Nervosa, Bulimia Nervosa, or Binge-Eating Disorder (Mustelin, Lehtokari, & Keski-Rahkonen, 2016). For the purposes of this paper, the term “Subthreshold” is used interchangeably with “Atypical.”

Anorexia Nervosa. As per American Psychiatric Association (2013), there are three essential features of anorexia nervosa: persistent energy intake restriction; intense fear of gaining weight or of becoming fat, or persistent behavior that interfere with weight gain; and a disturbance in self-perceived weight or shape. The individual maintains a body weight that is below a minimally normal level for age, sex, developmental trajectory, and physical health (Criterion A). Individuals' body weights frequently meet this criterion following a significant weight loss, but among children and adolescents, there may alternatively be failure to make expected weight gain or to maintain a normal developmental trajectory (i.e., while growing in height) instead of weight loss.

Bulimia Nervosa. As per American Psychiatric Association (2013), there are three essential features of bulimia nervosa: recurrent episodes of binge eating (Criterion A), recurrent inappropriate compensatory behaviors to prevent weight gain (Criterion B), and self-evaluation that is unduly influenced by body shape and weight (Criterion D). To qualify for the diagnosis, the binge eating, and inappropriate compensatory behaviors must occur, on average, at least once per week for 3 months (Criterion C).

Other Specified Feeding or Eating Disorder (OSFED). As per American Psychiatric Association (2013), this category applies to presentations in which symptoms characteristic of a

feeding and eating disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class. The other specified feeding or eating disorder category is used in situations in which the clinician chooses to communicate the specific reason that the presentation does not meet the criteria for any specific feeding and eating disorder. This is done by recording “other specified feeding or eating disorder” followed by the specific reason (e.g., “bulimia nervosa of low frequency”). Examples of presentations that can be specified using the “other specified” designation include the following:

1. Atypical anorexia nervosa: All of the criteria for anorexia nervosa are met, except that despite significant weight loss, the individual’s weight is within or above the normal range.
2. Bulimia nervosa (of low frequency and/or limited duration): All of the criteria for bulimia nervosa are met, except that the binge eating, and inappropriate compensatory behaviors occur, on average, less than once a week and/or for less than 3 months.
3. Binge-eating disorder (of low frequency and/or limited duration): All of the criteria for binge-eating disorder are met, except that the binge eating occurs, on average, less than once a week and/or for less than 3 months.
4. Purging disorder: Recurrent purging behavior to influence weight or shape (e.g., self-induced vomiting; misuse of laxatives, diuretics, or other medications) in the absence of binge eating.

Unspecified Feeding and Eating Disorder. As per American Psychiatric Association (2013), this category applies to presentations in which symptoms characteristic of a feeding and eating disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the

disorders in the feeding and eating disorders diagnostic class. The unspecified feeding and eating disorder category is used in situations in which the clinician chooses not to specify the reason that the criteria are not met for a specific feeding and eating disorder, and includes presentations in which there is insufficient information to make a more specific diagnosis (e.g., in emergency room settings).

Significance of the Study

By exploring my own journey with OSFED, I aim to increase my understanding of the biopsychosocial intricacies of disordered eating, the implications of having a concurrent chronic illness, and the pathway to healing. Through highlighting the cultural support for this condition, describing personal narratives, and articulating acts of resistance² through language and reframing narratives, my goal is to identify adaptive coping resources and effective treatments to enhance the effectiveness of counsellors (including myself) working with individuals experiencing complex internal turmoil, as well as highlight the sociocultural role connected to eating disorders. In addition, I hope that it inspires individuals struggling with disordered eating to build courage and persevere in recognizing, validating, and encouraging acts of resistance.

This would be helpful for practitioners working with patients who present with difficulties related to disordered eating and similar conditions in which their ability to lead a life worth living is threatened by barriers associated to emotional dysregulation, distress tolerance, perfectionism, and chronic stress. As this research addresses the role of chronic illness

² According to Lock, Epston, and Maisel (2005):

Narrative therapists work to disentangle the person from the problem, against the grain of the common constructions available in the resources of Occidental cultures that work to identify the person as ‘the problem’. This is demonstrated in the assistance they offer to people in finding ways to resist anorexia, by identifying anorexia as the problem, and not the person as anorexic.”

intertwined with disordered eating, it also provides insight and emphasizes the importance of specialists and general practitioners to increase awareness of extenuating challenges that may present when weight, nutrition, and dietary restrictions are inherent in the illness.

In approaching this autoethnography through the lens of my experience with OSFED, a subthreshold eating disorder less understood due to its more recent addition to the DSM-5, it may present additional insight and information contributing a deeper depth of understanding of this category. Through exploring the journey of disordered eating from diagnosis to recovery, this paper contributes more depth to understanding the multilayered challenges to prevention, treatment, and recovery of disordered eating, encouraging the support of community and multidisciplinary approaches.

My greatest hope is that this autoethnography contributes to broadening resistance to disordered eating through re-shaping societal awareness and responsiveness to the “problem,” through exposing misconceptions and offering meaningful perspectives of the deleterious effects of these practices. May this research bring forth courage to eliminate shame, reveal that which is hidden, and build a culture of resistance to rise up against disordered eating practices through education, understanding, and compassion.

Chapter II: Methodology

Introduction

Conducting a qualitative autoethnography through means of self-reflective accounts, analyzing journal entries, reviewing medical reports, engaging in therapeutic conversations, and interviews with significant others this research paper creates a narrative exploring the biopsychosocial and cultural complexities and challenges inherent in disordered eating through the author's lived experience with OSFED-Atypical Anorexia. Using autoethnography research allowed me to recognize, analyze, and challenge the personal and cultural effects of disordered eating and the cultural factors that perpetuate this condition. By giving readers insight into my experiences with OSFED, I hope to reveal the psychosocial and emotional impacts masked within eating disorders and the influence of westernized culture, dominated by male discourse, in its prevalence and detriment.

Ellis, Adams, and Bochner (2011) describe autoethnography as, “an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (p.1). Upon reviewing research on eating disorders, it became apparent that the majority of research on eating disorders are found within the eating disorders meeting threshold for, Anorexia Nervosa, Bulimia Nervosa, and Binge Eating Disorder, with minimal investigations and data of subthreshold categories, and even less research on the influence of chronic illness as a predisposing factor for these conditions. Despite OSFED sharing similar impairments and outcomes as eating disorders meeting threshold criteria (Fairweather-Schmidt & Wade, 2014), they often go undiagnosed and untreated (Thompson & Park, 2016) further complicating the damaging psychosocial and emotional effect on the individual, resultant socioeconomic costs (Rowe, 2017), and perpetuating the cycle of suffering.

Research on subthreshold eating disorders, namely OFSED, continue to need more focused research in order to increase societal understanding of the personal implications and cultural impact that is prevalent in the continually rising numbers of people affected by these life challenged disorders (Holmes, 2018).

Rather than the objective researcher trying to remove bias and disconnect self from research, autoethnography recognizes the value in the subjectivity and personal experience researchers can contribute (Wall, 2006). The subjective, lived experience is the true experience of the world and people around us. In an effort to enhance meaning and facilitate growth in my personal experience with OSFED, and to acknowledge the importance of the voices of those suffering with disordered eating, I connect research on eating disorders with this experience to facilitate relational understanding and increase my own understanding of my experience and perceptions (Bochner, 2012).

As I am eager to explore and understand my own experience of having a subthreshold eating disorder and the impact of being diagnosed with a chronic illness at young age contribute to research in this area, this study is presented in a Reflexive/Narrative Autoethnography.

Design: Reflexive/Narrative Autoethnography

Autoethnographic research appealed to me as I recognized a desire to explore and understand the cultural contexts that fuel, maintain, and often times act as a barrier to recovery in disordered eating. Although no experience is the same as another, the internal suffering entrenched in disordered eating is evident throughout the research. Research through autoethnography is a means of bringing this suffering the surface, so as to illuminate human connectedness, compassion, and understanding to revolutionize the dominating cultural discourses that illicit suffering.

Research on eating disorders reveals the significant impact of westernized culture's lack of understanding, and the stigma that perpetuates difficulties with identifying and treating disordered eating. Coming to terms with the eating disorder has been a difficult process; however, I realized that I could make meaning of these challenges and contribute to growth personally and within research to better understanding a complex illness, affecting many women in society. Through the lens of a narrative autoethnography, I have integrated my personal experiences living with a subthreshold eating disorder with research, to captivate, educate, and engage readers in understanding the personal and cultural implications of OSFED. In discussing the impact of autoethnographic research, Philaretou and Allen (2006) suggest:

Researching sensitive issues or “taboo topics” ultimately proves beneficial to the social science community since such issues tend to (a) attract considerable attention due to their controversial nature, (b) allow social scientists to apply scientific techniques and processes to delve into their nature, thereby helping to dispel myths and misconceptions, (c) beg for investigation as they oftentimes lack adequate formal scientific information as to their etiology, and (d) create a basis for building an understanding and an expanded knowledge basis about related social-psychological phenomena. (p.66)

The exploration of my personal experiences with OSFED takes on a story-line approach, that is indicative of a narrative style of approaching autoethnographies. According to Ellis et al. (2011) “Narrative ethnographies refer to texts presented in the form of stories that incorporate the ethnographer's experiences into the ethnographic descriptions and analysis of others” (p.4). As I felt the research and writing process contributed a great deal to changes in my understanding and relationship with disordered eating practices, the narrative approach also incorporates reflexive ethnography means in composing this autoethnography. According to Ellis et al. (2011)

“reflexive ethnographies document ways a researcher changes as a result of doing fieldwork”

(p.4). Ellis et al. (2011) explained:

Reflexive/narrative ethnographies exist on a continuum ranging from starting research from the ethnographer’s biography, to the ethnographer studying her or his life alongside cultural members/ lives, to ethnographic memoirs or confessional tales where the ethnographers backstage research endeavors become the focus of investigation. (p.5)

Beyond the implications autoethnography research has on the social science community, it simultaneously helps to empower the research in their own understanding and healing of the sensitive topic being discusses (Philaretou & Allen, 2006). Engaging in autoethnography has the ability to produce therapeutic writing for the author; it requires personal reflection, produces questions, involves analysis, and can give meaning to the author’s lived experiences (Ellis et al., 2011).

Participants and Procedure

Using myself as the sole participant and clinical case study, I have explored my own journey living with an eating disorder. Although I am exploring my own experience with OSFED, I recognize that eating disorders are multifaceted and do not generalize my experience as that of others who have an eating disorder. My experience with an eating disorder focuses on OSFED and the interplay of having a kidney disease. As such, personal experiences, reflections, and accounts focus on my lived experience with this. Discussions and insights regarding eating disorders in general, and beyond OSFED are based on research, and contribute to my knowledge and understanding of these disorders at large. At times, I connect and relate my personal experiences with research of other categories of eating disorders, due to lack of research in OSFED, overlaps and similarities with other categories, and to enhance understanding of my

personal experience as well as that of others who suffer with an eating disorder. Engagement in research demands that the researcher hold themselves to the highest standard of ethics to prevent participants from undue harm.

Two more commonly understood and universally recognized ethical dimensions include “Procedural” and “Situational” ethics. According to Guillemin & Gillam “Procedural Ethics” are those in which the researcher must obtain informed consent, address confidentiality, right to privacy, deception, and protect human subjects from harm (as cited in Ellis, 2007, p.4). Explained by Goodwin, Pope, Mort, & Smith “Situational Ethics,” are those in which the researcher must adequately and responsibly attend to unpredictable ethical situations as they arise (as cited in, Ellis, 2007, p.4). Ellis (2007) identifies the importance of including a third dimension of ethical responsibility in autoethnography research due to the innate relational associations unique to this method. Ellis (2007) claims “Relational ethics recognizes and values mutual respect, dignity, and connectedness between researcher and researched, and between researchers and the communities in which they live and work” (p.4). Life is relational. Lived experiences happen in the context of relationships and interactions with those directly involved in our lives, culture, and the world around us. Gergen (2009) states “the concept of relational being should ultimately gain its meaning from our ways of going on together” (p.xv). It is imperative that eating disorders be addressed in relational contexts, to challenge the isolation they demand of their victims so prevalent in an individualistic society where it thrives.

According to De Toqueville:

Individualism is a mature and calm feeling, which disposes each member of the community to sever himself from the mass of his fellows and to draw apart with his family and friends, so that after he has thus formed a little circle of his own, he willingly

leaves society at large to itself...individualism, at first, only saps the virtues of public life; but in the long run it attacks and destroys all others and is at length absorbed in downright selfishness (as cited in Gergen, 2009, p.12)

As a researcher, I have an ethical obligation and responsibility to protect both my own well-being, as well as that of others who may be implicated through relationship to me or otherwise from any type of psychological, social, emotional, or physical harm. I adhere to all the ethical elements by obtaining informed consent from anyone who is implicated in the research due to their relation to me, permitting them to view the autoethnography before finalization, making adjustments as necessary to protect both myself and others, and addressing relational ethics throughout the process of research as challenges arise. Beyond this, I engage in therapeutic conversation and self-care to protect myself from harm that may arise through recalling and reflecting on personal challenges throughout the course of the autoethnography research.

The biographical aspect of the autoethnography is attended to through journal entries, reflections, and 'epiphanies' that arise throughout the writing process, inner conversations, and dialogue with others (Ellis et al., 2011). Furthermore, epiphanies and meaning are derived through personal journals, discussions in therapy sessions, and experience through participation in Dialectical Behaviour Therapy where information could be processed on a deeper level. Perspectives come from both a hindsight and current view of experiences. The ethnographical aspect is covered by addressing westernized culture's values and beliefs about eating disorders.

Journal entries are important to include in the research as they relay the most accurate information regarding my state of being, events, and lived experience at the time it occurred. Reviewing medical records provided verification for accuracy of reflective accounts in connecting internal distress that unfolded through medically-related events with the onset and

maintenance of disordered eating practices. Unfortunately, it is not possible to have a written record of all pertinent information regarding personalized experiences; therefore, I incorporate reflections of prior events and interpret meaning to support deeper levels of understanding the impact of those experiences in relation to my recovery journey. To increase the accuracy of recollections where events and internal state collided, I have sought the input and perceptions of others involved to help me recall and relay the most accurate account.

Data collection primarily takes place through journal entries, recollection of memories, reflection of therapeutic discussions, and medical notes. I continue posing research questions to myself throughout the duration of my research to further explore the connections of my life experiences that interacted with the eating disorder. As I go through this process, I will be asking myself questions such as: "How is the disordered eating and experience with emotions interrelated?" "What techniques have been helpful in learning to work with emotions in healthy ways?" "What are specific challenges I experience with having a subthreshold eating disorder?" "What factors contributed to an adulthood onset of OSFED?" "What are the societal and cultural implications of eating disorders?"

Analysis

Using a reflexive/narrative approach of autoethnography elicits first-person experience to understand how eating disorder practices were influenced and presented in my relationship with OSFED-atypical anorexia. The narrative methodology facilitates engagement through reflecting, retelling, reconstructing, and analyzing my story through a personal and research perspective. Philaretou and Allen (2006) suggest that participating in research in this manner, has the ability to empower the author to see alternative views and narratives, thereby creating pathways for positive change and growth.

In reflecting on my journey through treatment and recovery I identify a catalyst of onset through predispositions incumbent in challenges associated with a chronic illness. Additionally, I investigate the challenges accepting behaviours as disordered eating practices, recognition of need for treatment, and difficulties accessing supports to facilitate recovery. Furthermore, I link therapeutic conversations and utilization of Dialectical Behaviour Therapy (DBT) strategies that initiated epiphanies and engagement in reflection, in conjunction with conversations among family members and friends to create a more accurate representation of my experience with OSFED.

Dennstedt (2010) writes of the importance, necessity, and value of including the voices of those that we research within the research itself, suggesting that honoring the individual's knowledge and experiences in responding to, navigating, and engaging in acts of resistance, facilitates a profound depth of understanding the person and the problem. By honoring my own voice through presentation of autoethnography research, it will help me to better understand how my journey unfolded, engage in healing, and acknowledge acts of resistance. Ellis et al. (2011) argued that “writing personal stories can be therapeutic for authors as we write to make sense of ourselves and others” (p.5). My hope is that this research will unveil the mask of perfectionism, a culture of ‘thinness’, and control to expose the shame, stigma, and isolation, that lay buried within, challenging society to engage in this issue.

Philaretou and Allen (2006) suggest “autoethnographic research is conducted by interpreting personal documents, letters, and recollections of important events in a person’s life through the process of account making” (p.66). As such, I use recollection, recall, interviews with my mother, and therapy to understand the implications of my experience of childhood events on the trajectory of the eating disorder and the catalyst for onset in adulthood, and further

experiences with OSFED. Journal entries and ongoing epiphanies were noted and included in the documentation of this autoethnography to contribute understanding of the recovery process, the challenges faced, and the adversities overcome.

Engaging in research and recovery illuminated themes that facilitated organization of personal data collection, giving structure to the process and writing. Speaking to themes, Philaretou and Allen (2006) suggest, “the categorization of the autoethnographer’s personal accounts into general themes and by-themes provides easy, clear, and concise ways of grouping the qualitative personal data into intelligible categories and making sense of them” (p.68). Themes identified include risk factors, onset, treatment, and recovery of OSFED through a life-course perspective (Philaretou & Allen, 2006).

The autoethnography begins boldly by giving the reader perspective of what my experience with OSFED looked like at its worst, then transitioning to retrospective research of risk factors identified in symptoms and management of a chronic kidney disease and the interaction of life stressors contributing to the onset and trajectory of OSFED. The autoethnography concludes with analyzing the treatment and recovery process. Treatment and recovery are addressed through an exploration of personal challenges and barriers that arose through levels of acceptance, maladaptive behaviours of perfectionism, control, and emotional dysregulation inherent in the disorder, followed by systemic barriers to accessing to treatment. Cultural implications of belonging to a culture dominated by patriarchal discourses are addressed and revealed through connecting research to personal experience as an overarching theme in the autoethnography. The end of my journey through this autoethnography addresses the impact of adopting mindfulness practice and the necessity of co-creating a community of care to combat in resisting disordered eating.

Ethical Considerations

I felt engaging in an autoethnographic approach to my experience living with an eating disorder would be the most beneficial way to contribute to the social science research of subthreshold eating disorders, namely OSFED. Although the drawbacks of this method of research can involve concerns regarding trustworthiness, verification, and potentially embarrassment of harm non-consenting individuals (Philaretou & Allen, 2006), I have taken measures to reduce the disadvantages of this research method. As such, informed consent has been obtained by any individuals who could be identified through familial relations and have received Institutional Review Board approval from City University of Seattle in Canada. These participants have also been granted permission to review all aspects of the thesis before it is completed. As my research will inevitably identify people that are close to me, such as my mother or father, I have been astute in identifying and protecting relational concerns (Ellis et al., 2011). Identifiable characteristics are minimized whenever possible; however, when identifiability was unavoidable, I shared my work with those involved to give them an opportunity to respond and engage in the research, followed by addressing and rectifying any concerns.

Philaretou and Allen (2006) discuss some of the challenges autoethnographers experience and need to be aware of as, “Psychological and emotional equilibrium lends itself vulnerable to disruption/strain because when we write about ourselves, we come to unmask its limitations and weaknesses” (p.71). As such, I also needed to be aware of how completing an autoethnography would affect my own well-being; and reduced harm that could arise as a result. In order to protect myself and reduce personal harm I continued to seek professional assistance in reducing and ameliorating any challenges that I transpired as a result of engaging in autoethnographic writing. I continued to maintain support through family, friends, therapy, and group

programming throughout the course of the autoethnography. Additionally, I expanded my self-care and coping regime, to incorporate holistic methods, and further increased adaptive coping strategies.

Conclusion

The methodology provided explains how I came to decide that the best method of facilitating this these was through the lens of a reflexive/narrative autoethnography approach. I have also provided a detailed explanation of how the participants, and other persons involved in the autoethnography have been protected through non-identifying means, changes in time frames, informed consent, and engaging in necessary revisions to maintain anonymity and minimize harm. The framework of the autoethnography, based on levels of acceptance and complexity of barriers associated with disordered eating is analyzed through the reflection, re-telling, reframing, and connection of current research through my lived experience with OSFED and chronic illness. experiences from childhood to adulthood that connected to the trajectory of my adulthood experiences with OSFED. Finally, I have explained how this autoethnography addresses the societal and cultural norms of westernized society contribute to disordered eating, making it a societal issue in need of further education and research.

Chapter III: Kidney Disease, Internal Distress, & Disordered Eating

“Do you take any illicit drugs?” asks the nurse completing my hospital intake. A brief pause indicates my apprehension to respond with my mother standing beside me. “Oh, sorry I’ll come back to finish this,” she says sheepishly recognizing we were in an awkward predicament. Realizing I’ve got nothing to lose I respond, “No no, it’s okay, I don’t care” and proceed to answer her question. As the nurse exits the hospital room my mother says, “I don’t blame if you do, it would probably make you feel better!”

Being diagnosed with a kidney disease in adolescence tasked me with an immense and immediate responsibility to change how I lived my life. In order to control some of the symptoms, under the direction of my doctor and dietician, I needed to embrace a completely new diet and life style to accommodate the complex facets involved in living with and treating this disease. As an adolescent, the challenges I experienced as a result of the kidney disease remained manageable. It wasn’t until I was an adult that these challenges become unmanageable. As life stressors increased with age, so did the psychological challenges I experienced as a result.

In reflecting on my experience with OSFED, I recognize the significant impact having a chronic illness has had on the development and maintenance of the eating disorder. The challenges I faced managing a kidney disease increased the threat of developing an eating disorder later in life, adding another challenging element to treatment. Overtime, the symptoms of the kidney disease severely threatened my body image, challenged my ability to cope, diminished my self-esteem, and initiated an immense need I had to perfect and control everything in my life. In their investigation of eating disorder risk among patients with Type 1 diabetes, Powers, Rickter, Ackard and Cronemeyer (2016) identify challenges with feeling

different, body image, difficulty with control and coping, and feelings inherent in managing Type 1 diabetes as risk factors for developing an eating disorder³.

The hypervigilance, perfectionism, and perseverance I developed as a means of facilitating kidney health evolved into perfectionism in life, hypervigilance of nutrition labels and calories, and a perseverance to continually lose weight as fuel that later served to initiate and sustain destructive behaviours associated with disordered eating.

Symptoms

As an adolescent I adapted quite well to living with a kidney disease. I was only accountable to myself, had little responsibilities, and felt quite resilient to the few challenges and hurdles that presented with it. I maintained the ability to be independent, successful, engage in socially normative ways, and felt I positively managed a good balance between the demands of life and that of my kidney condition. Four years after the diagnosis it went into remission; it was not until the condition resurfaced as an adult, in a different stage of my life that it became increasingly problematic. Powers et al. (2016) argued that navigating normative challenges in adolescents with experiencing the additional stress of managing control and coping, body image, and feelings associated with chronic disease, increases the risk of developing an eating disorder. Re-experiencing the kidney disease at a time in my life when pressure and stress had drastically increased from the initial onset, added significant challenges to managing and balancing normative life events and a chronic illness.

³ Although I do not have Type 1 diabetes, I view my kidney disease in parallel to the challenges experienced with this illness. Where insulin is used to manage diabetes, I would use diuretics. The necessity of dietary restrictions and body fluctuation are similar. The diets required are different (sugar management vs. sodium management); however, the challenges associated with the experience are also similar.

The worst symptom of the kidney disease was the edema⁴. With gravity working at full force, every morning I awoke with a plump, round, face and stout, heavy legs in the evening. Evenings were unbearable; the skin on my legs were stretched so tight it felt as though it would tear and bending at the knees exacerbated the pressure and discomfort. Imprints in my skin left from socks, shoes, and pants made looking at my legs intolerable. They were disgusting. I stopped wearing skirts or dresses wherever possible, and strategically planned for evenings in which I needed to wear an outfit that showed my legs. My strategy involved working with gravity, in which I elevated my legs for several hours before getting dressed for an evening out. I masked the incredible psychological distress I was experiencing with weight gain (attributed to edema) and visibility of it with humour. I joked that my legs were like the Pillsbury Dough Boy; you could push the skin on my leg and leave an indent that would stay there for several minutes. Pitting⁵ my skin became a party trick; one that I learned to use to make myself feel better by displaying that it was not fat; rather, that it was fluid retention. I highly valued people's perceptions of me. I thought that if I was forth coming, then they wouldn't need to wonder, and making it a source of humour, in my mind, made it less likely they would think I was fat.

For most women living in westernized society, body image is a highly concerning and distressing issue they face (Peat, Peyerl, & Muehlenkamp, 2008). The constant felt and visible fluctuations my body experienced as symptoms of the kidney disease severely threatened my self-esteem and body image. As explained by Peat et al. (2008), "Researchers have shown body image to be an important part of a person's self-concept and have linked body dissatisfaction to

⁴ Edema: An accumulation of an excessive amount of watery fluid in cells, tissues, or serous cavities (Edema, 2002)

⁵ Pitting: The formation of well-defined, relatively deep depressions in a surface (Pitting, 2002)

various psychopathologies, most frequently eating disorders” (p.343). In conjunction with this finding, dissatisfaction with body image increases the risk of acquiring psychological dysfunctions (Peat et al. 2008). Through adolescence and adulthood, I aspired to be thin. I always viewed thinness as a necessary element of beauty, and therefore a measure of attractiveness; in which I was not living up to. Despite my lifelong beliefs around body shape, size, perception of my own body image, and self-esteem I never experienced any of these as a pervasive issue until it penetrated my every day through the symptoms and management of my kidney disease.

Living with a condition that constantly changed my physical appearance, I was frequently involved in conversations where people commented on and initiated discussion about the noticeable fluctuations of my body weight and shape. In reflecting on my experience with body image and self-esteem, it became apparent how often people inquired on the status of my kidney disease in relation to visible changes in my body. I was constantly faced with people verbalizing their observations of my swollen face or legs and explaining my condition to others who may have been unaware; further bringing my attention to them noticing that I looked bigger. I would also get the opposite comments about looking smaller, followed by comments that I must be managing the low-sodium diet well or the kidney disease must be getting better. Internalizing the constant commentary, I felt an immense amount of pressure to perfect my diet. Commentary on observable edema was internalized as me not having enough discipline adhering to a low sodium diet.

Buried Emotions

From the time I was diagnosed, I was adamant that I would not succumb to the disadvantages that came with the kidney disease. Come hell or high water, I was not going to feel sorry for myself and I most certainly would not be upset about it. I vowed to persevere, work

harder, and prevail at achieving all milestone expectations of life around family, career, health, and wealth. At all costs, I refused to become a victim to my illness. I relied on this outlook to survive the frustrations of how unfair I felt life was and there being no logical explanation for me having this physical illness⁶.

My entire life, I viewed emotions as “good” and “bad”, determined by which emotions felt comfortable and those that were intolerable. Sadness, anger, and (particularly) disappointment were emotions I avoided. The ability to regulate emotions develops over the lifespan, beginning with interactional experiences in early childhood with caregivers (Monell, Hogdahl, Mantilla, & Birgegard, 2015). I had a lifetime of practice in ignoring these feelings existed, burying them through distractions, and masking them in silver linings. I was protecting myself from feeling pain. Viewing my emotions in this manner made me feel that I could control them. If I chose to ignore the pain, I would not feel the pain; If I ignored the anger, I would not feel the anger.

Wanting to spare myself and others the pain, sadness, and despair I experienced in managing a chronic illness I found silver linings for everything, thinking *At least if I'm getting bloodwork all the time, I'll know if there's anything else wrong; a restricted sodium diet isn't that bad at least it means I'm eating really healthy; Having all this extra weight has given me the opportunity to appreciate and empathize for how difficult some things are for people that are bigger.*

⁶ Despite rigorous and persistent bloodwork, biopsies, and research into my family's history of illness over several years, doctors were unable to determine a cause for development of a kidney disease. They began discussing the potential the symptoms of the kidney disease could be progressive lupus. After several more years, with no additionally developing symptoms, the doctors settled with the cause of the disease being “idiopathic.” Thus, there was no reason or cause for developing a kidney disease.

Even as a child, I could not bear the feeling of guilt and remorse I felt in causing distress, sadness, or anger in others. I preferred taking on what I experienced as negative emotions alone. I felt keeping them to myself and bearing the burden of them was better than inflicting these unbearable emotions on someone else. Burying the emotions allowed me to cope with day to day distress I experienced with feeling different, and the psychological challenges that surfaced through the illness. Discussing the role of emotional dysregulation in eating disorders, Monnel et al. (2015) explain avoidance of expressing feelings to others as one of the contributing factors in the maintenance of eating disorders. I thought that being able to control my emotions in such a way was healthy, and indicative of healthy emotional regulation. It was not until the pressure of constantly suppressing my feelings began to erupt in destructive displays of overwhelming emotion, that I began challenging this notion. Monnel et al. (2015) identify emotional regulation as the “acquired ability to recognize, understand, and accept one’s emotions, as well as strategies to modulate the experience and expression of emotions in line with long-term goals and values” (p.2). The way I began to experience emotions displayed everything other than this. At times, when the feelings and emotions became too much to suppress, all that was inside would erupt to be absorbed in the many secrets and scars the walls of my car kept contained. The thoughts relentlessly invaded, *this is too much; I don’t want to increase this dose of medication. Look how fat my legs. My skinny jeans are suffocating my fat legs, the pitting looks disgusting, “AHHH, AHHH, AHHH.”* Hayno & Fruzzetti posit, “High intensity and/or long duration of emotional arousal increase the risk of emotional dysregulation to in response to everyday emotional events” (as cited in Monell et al., 2015, p.4). Sobbing to the depths of my despair and screaming with the force of my entire body, I unleashed every feeling that was locked away. Although it only lasted

about 5 or 10 minutes, these outward expressions of despair, anger, and overwhelm I felt inside left me completely exhausted, but relieved. Masking my distress under an appearance of strength and resiliency, ultimately led to suffering in isolation.

Time for A Change

Years after the kidney disease resurfaced, I was inspired to change my relationship with the kidney disease by the desire to have another child. This desire gave me initiative to regain control of my physical health. I gained a fair amount of weight after my first pregnancy and wanted to lose the weight I had gained before having another pregnancy, as well as reduce the edema that had been an ongoing challenge. I believed that by re-engaging in a sodium restricted diet and exercising regularly, I would be able to gain control of my weight and the kidney disease at the same time. I saw losing weight as the solution to bettering my relationship with the kidney disease and increasing my ability to have a healthy pregnancy. As a lot of the weight was fluid-retention, I felt that the best method to get rid of the fluid and quickly adapt to my no-sodium restrictions was to start a “Cabbage Soup Diet⁷.” People told me that this diet does not work well because the person is mostly losing fluid, rather than fat. In my circumstances, with having so much extra fluid in my body, it sounded perfect for me. I saw this diet as a way to lose the excess fluid, as well as facilitate a quick transition back to the no-sodium diet I had taken up when I was first diagnosed with the kidney disease. One Cabbage-Soup Diet that was supposed to last only 7 days, turned into several weeks. Within a few months, I had lost a substantial amount of weight.

⁷ The cabbage soup diet consists of severely restricting caloric intake for 7 days through strictly adhering to consuming specific foods. It is meant to provide weight loss seekers with jump start to their weight loss and not intended to be used as a long-term solution (Watson, n.d.)

The more weight I lost, the more I received positive reinforcement that perpetuated my desire for continued weight loss. The kidney disease started to get progressively better; I was able to slowly reduce medications, people started commenting on how great I looked (a shift from the sympathetic commentary of weight gain), shopping for clothes became enjoyable because everything fit, I could sit comfortable in chairs, sit crisscross on the floor, and had much better cardio running around after my young child. The positive reinforcement I received and the increase I felt in my self-esteem, were enough to fuel my fire to continue losing weight. At some point, without cognizant awareness, my focus on sodium intake evolved to incorporate caloric intake.

In reflecting on this time in my life, I am able to recognize the intrusive, negative, persistent thoughts as the voice of ED. He utters, *I'll be so happy if I can get back to my high school weight*. My target weight became 150lbs. Reaching 150lbs ED says, *I need to lose more weight to create room for margin of error*. My target weight became 145lbs. Reaching 145lbs ED declares, *Body Mass Index (BMI) says 145lbs is on the high end of the healthy range; that's unacceptable, I need to be 140lbs*. When 140lbs became the new target weight, I recognized a pattern of increased pressure I put on myself to lose more and more weight. Identifying this pattern, I promised myself that this was the last reduction, and I could prove to myself that I didn't have a problem because I had the discipline to stop at 140lbs and feel satisfaction at that. The fixation I had towards losing weight became increasingly problematic and snowballed, picking up traction on intrusive thoughts and maladaptive behaviours. The more weight I lost, the more intrusive and destructive my thinking and self-criticism became. I began to see every problem I had as a problem with my weight or the way I looked. I started to view my appearance as the sole problem in my marriage, which was preventing me from having more children.

Symptoms of the eating disorder worsened in the dissolution of my marriage. Coping with ever-increasing pressures and stress exacerbated my need for control, desire to lose weight, and challenges tolerating emotions. I felt shame, guilt, remorse, and completely responsible for not being able to maintain a nuclear family I so desperately desired. The aspiration to lose weight never stopped, my self-concept became increasingly distorted, and I began to blame myself for any problem that occurred. My mind was consumed with a need to work out, control my diet, decrease my weight, and an endless list of perpetually destructive disordered eating behaviours.

I Do not Have an Eating Disorder

The unusual challenges I experienced preparing for and the aftermath of a difficult surgery, were the catalyst that drove me to seek out professional help for the internal struggles I was experiencing. Feeling immense pain, lack of mobility, and constant lethargy from pain medication in post-surgery, I was overcome with relief, happiness, and decreased stress in the post-surgery nausea because I was not eating, and instead of gaining weight I was losing it. The further along I got in my recovery from surgery and regained my appetite, the worse my behaviour and thoughts around weight loss, body image, need for control, and emotional distress worsened. It was not until I had this operation that my concerns with what I was experiencing rose to a level that I felt was worth discussing with a mental health professional. I realized whatever I was experiencing (eating disorder, or otherwise) was not going away on its own, and I could not fix it myself.

Utilizing outpatient supports, accessible to me as a patient of the kidney clinic, I had the opportunity to express my concerns regarding my continued desire to lose weight, and the internal distress to a mental health professional that could help me to identify and connect with any further supports I needed; alternatively, they could validate and normalize my experience as

what most women in my circumstances experience. I cannot recall the content of the conversation with this person; however, I vividly connect with the outcome that unfolded in the following months. Although I recognized I was experiencing challenges, at the time, I was oblivious to how deep and detrimental they were. The idea of me having an eating disorder was unacceptable on many levels and not an avenue I wanted to explore. I reject this, *I'm not underweight, I'm still eating, I'm not puking, I don't meet diagnosis for anorexia or bulimia (I checked) so it's not an eating disorder, right?"*

I believe that, at the time, sub-consciously I knew I was experiencing a serious mental health issue, but the cognizant part of me was seeking out a mental health professional to confirm my hopes that I did not have a problem, and these were normal thoughts and experiences of women in a culture of “thinness” combined with stress of being a single-mother. Sharan and Sundar (2015) argued that, “The overvaluation of slimness, which is commonly seen in Western females, is considered to be an important contributory factor in the pathogenesis of eating disorders” (p. 286). According to Preyde et al. (2016) eating disorders affect 5% of women in westernized countries. Research indicates that the steady increase in eating disorders (Guinzbourg, 2011) in developing countries is a result of cultural transformations associated with westernization (Sharan & Sundar, 2015). According to Lee, Ho, and Hsu prevalence of “fat phobia” in the etiology of eating disorders differs between western versus non-western, in which they discovered this criterion to be more indicative of disordered eating practices in westernized cultures (as cited in Sharan and Sundar, 2015, p.288). Moreover, Becker, Thomas and Pike posit fat phobia is an element of eating disorders most commonly found in patients of westernized countries diagnosed with an eating disorder, and less commonly associated with eating disorders

in non-western countries where starvation may be more attributed to the economy (as cited in Sharan and Sundar, 2015, p.288).

The first appointment with the psychiatrist did not go well. I was shocked to discover during this appointment that she was an eating disorder specialist. As I described my challenges from a lens of normalizing my experience as woman and single mother, the psychiatrist was not in agreement that what I was experiencing was typical. She proceeded to explain the emotional challenges, thoughts, perfectionism, and need for control that I experienced as symptoms of an eating disorder. I thought, *she doesn't know anything about me! She just met me. It's not possible to diagnose me with something so ridiculous in one hour. I know for a fact I'm not anorexic, and I definitely don't puke so I can't be bulimic.* I was extremely defensive and relentlessly explaining that I did not meet criteria for anorexia or bulimia, and therefore did not have an eating disorder. Over the next few months, I intermittently attended counselling sessions with the psychiatrist. Unable to connect with her assertion that I had an eating disorder, I had difficulty committing to seeing her on a weekly basis and questioned, *why would I miss work to see an eating disorder specialist on a weekly basis, when I don't have an eating disorder?* Believing so firmly that I did not have one, I was scared that if I continued to see this psychiatrist she would get in my head and I would actually develop one. After a few months, the psychiatrist gave me an ultimatum; I needed to commit to attending sessions weekly or decide it was not for me. Hesitantly, I reason, *I don't have an eating disorder, but I'm not an eating disorder expert. I know a lot about psychology, but I know nothing about eating disorders. What if this psychiatrist is right? What if I do have an eating disorder and I pass up on this opportunity to get help and then things get worse and I come to my own conclusions that I have one too late?* Knowing that psychiatrists are extremely hard to come by and that this option isn't available to many who need

it, I decided that I could not take the chance that she was right and let this opportunity pass by; even if, at the time, I did not believe her.

A Rough Start

Going to therapy was extremely painful. In the beginning, I thought that getting time of work to go to this appointment would be a great way to spend a Friday afternoon; I was completely wrong. Going to therapy was awful. I was sitting across the room from someone who had a completely different perspective of my situation than I did. For many months, I worked to exhausting lengths avoiding any conversation that could validate I had an eating disorder. I would not discuss distressing thoughts I continued to have regarding my body image, self-hatred, self-harm, constant exercise, unbearable levels of stress, and ongoing challenges with my emotions. I finally felt relief in a session where my psychiatrist voiced that she was not there to convince me I had an eating disorder, but rather that we would be going on a journey to see where this goes. I felt relieved that I did not have to work so hard skirting around eating disorder talk. She took this time to get to know more about who I was, my childhood, and life experiences. For the first several months, I gave her a run-down of how fortunate I was to grow up in the family I did, the amount of support and love I received throughout my life, and how lucky I was to have my life be the way it was now. I went on to paint a picture of silver linings around every adversity I faced in life. These narratives played on a loop for years, *my dad died when I was young, but there were challenges when he was around so it probably worked out for the best in the long run; I live with a chronic illness, but it's not that bad because I'm not on dialysis and it's under control and I'm probably healthier than I ever would have been at this age because of the restricted diet; I had an unexpected pregnancy at a young age, but I persevered through post-secondary and that kid is amazing; Yes, I'm separated, but it's all good*

cause he's a great dad and we parent well together. Once in a while, the psychiatrist would throw me a curve ball that would challenge my perceptions, poke holes in my silver linings, and educate me on eating disorders; which I was continually resistant to accepting. Those silver linings were my life line, my way of surviving, persevering, and resisting being crushed by life. It's how I had spent my entire life protecting myself and getting through life's adversities coped, and the only way I knew how; silver linings, suppressing emotions, independence, and perfectionism.

I did not know anything about eating disorders other than the symptoms of anorexia and bulimia. I was unaware of the immense psychological and emotional challenges ingrained in them. Like much of the public, I thought they were about having a negative body image, constant struggles with dieting, and wanting to be thin, which led to behaviours of restricting food intake or purging (Salafia, Jones, Haugen, & Schaefer, 2015). I never thought of them in terms of what internal struggles a person faces to get to a point that they have these behaviours. I only thought of them as behaviours. The psychiatrist suggested that I read "Life Without Ed" by Jenni Schaefer to give me a better understanding of the lived experience of someone who has an eating disorder. Although, at the time, I could not relate to Jenni Schaefer's use of "ED" as a means of externalizing the problem, thus separating herself from the eating disorder, and creating space to identify ED as the voice of her eating disorder; I was shocked at how similar many of her internal thoughts were to mine⁸. The more she described her thoughts and behaviours, the more my adamant denial of having an eating disorder broke down and was brought into question.

⁸ In the beginning, when I could not identify having an eating disorder, I wasn't able to understand the concept of distinctly identifying the voice of an eating disorder from one's own voice; only to completely identify with this as my eating disorder unraveled.

Expanding my understanding of eating disorders through this book facilitated some discussions of these similarities I noticed in sessions with my psychiatrist and cracked open the door for me to share bits and pieces of the internal struggle I faced.

I was diagnosed with Other Specified Feeding and Eating Disorder- Atypical Anorexia Nervosa (American Psychiatric Association, 2013). This category of eating disorders was added to the DSM-5, established in 2013 (American Psychiatric Association, 2013). The complexity, severity, and etiology of eating disorders requiring a multidimensional approach to treatment continues to challenge mental health professionals and researchers in categorizing, diagnosing, and treating them (Holmes, 2018). Where experts and professionals are met with many barriers understanding and treating eating disorders, it is understandable why society struggles so much to understand, recognize, and support those who struggle with these mental health challenges; as well as why it can be even more challenging for those who are living with an eating disorder to come to terms with it. Much of the knowledge (or lack thereof) and perspective society takes on disordered eating stigmatizes it, further adding to the complexities and barriers associated with eating disorders (Salafia et al., 2015).

The more I saw the psychiatrist, the more informed I became on what eating disorders were, how they affect people, and the characteristics that make them what they are. I began learning that eating disorders of all types were not solely about food and weight; rather, that they are a biopsychosocial problem (Holmes, 2018) further complicated by maladaptive behaviours. I began to grasp that categories of eating disorders extended beyond the threshold ones of Anorexia and Bulimia. I learned that OSFED was just as viable, real, and serious as any other classification of eating disorder. As my level of education of these disorders expanded, I began to

understand my relationship with eating disorder practices and their presentation as OSFED-Atypical Anorexia.

With my new-found knowledge I decided that I would see what a friend's thoughts on the subject were, before I truly bought into it. I met with a friend one day and mentioned that I was seeing a psychiatrist who felt that I had an eating disorder. Although I was skeptical about telling them, I needed to know what other people thought and how they would respond to knowing this about me (if it was indeed true that I had an eating disorder). My comment was met with dismissive facial expressions, words of disbelief, and refuting I had an eating disorder. I despise my myself and consumed by negative thoughts, *I'm so stupid! I knew not to say anything. Why would I do that? Even if I have an eating disorder, no one can help me, and no one will believe me. I'm not underweight and I'm not puking; I'm even fatter than most my friends. I just sound like I'm looking for attention. I'm so stupid.* I felt stupid and completely ashamed that I had shared what was going on for me. According to Mustelin et al. (2016) "Residual diagnostic categories are frequently dismissed as 'not really serious' despite substantial evidence to the contrary" (p.1015). Testing my foot in the waters to see how someone would react to me sharing this information completely backfired. I regressed further into myself. I became more self-conscious eating around people, hid any appointments I was going to regarding the eating disorder, and would not even share this information from doctor to doctor.

As time passed, I settled down and chalked the conversation up to not confiding in the right person. I gained the courage to tell one more friend. I was looking for someone who would be open to listening how I experience this, who could convince me that I really did have an eating disorder and should listen to the psychiatrist. My disclosure to the second friend was met with same disbelief, contradictions, and pointing out that I was not underweight or puking, so I

did not have an issue. These people said, “there’s nothing wrong with you.” They normalized the desire to lose weight and want to look good. I made the decision that, even if I did have an eating disorder, I would bury this information to prevent feeling foolish in the future. My experience with people in my social network revealed the negative impacts that the society I live in could have on me if I exposed what I was going through. It was not their fault that they lacked understanding of eating disorders. They had the same perception that I had when I was first challenged with expanding my knowledge beyond eating disorder. I was thankful that I began to see a psychiatrist when I did, because I realized that no one else in my social network or community would understand or be of any help, and in fact, were making my ongoing struggles with the eating disorder much worse. In their article detailing perceptions of eating disorders in people with and without an eating disorder, Salafia et al. (2015) explain,

Despite the potentially serious health consequences that result from disordered eating, many in the general public believe that issues with eating are due to personal shortcomings. This creates a foundation of stigma regarding why individuals develop an eating disorder and the purpose it serves...In turn, those developing unhealthy habits may be discouraged from seeking help. (p.4)

In my view, *If the rest of the world doesn't take my eating disorder seriously then, how can I? I won't be that person who looks like they've got some fake mental health issue that they're overexaggerating. Things are really not THAT bad. I'm still a normal weight and I still eat. Of course, I want to lose weight; what woman doesn't? The only reason the psychiatrist thinks I have an eating disorder is because that's what she sees day in and day out. What if she's convincing me I have an eating disorder when I don't?* The only person who seemed to believe I had an eating disorder was the psychiatrist. I continued going to see this psychiatrist, not because

I believed I had an eating disorder and needed help, but because I could not take the chance that she was right. If she was right, then I really did know absolutely nothing about eating disorders.

A Time to Accept

I will never forget the conversation that changed my ability to engage in therapy and bridged the gap I felt between the psychiatrist and myself. I had been going to therapy for almost a year. Every week, begrudgingly, I managed to attend every appointment. One day in the spring, as a session was ending my psychiatrist engaged me in a last thought:

Psychiatrist: “Jodie, do you think that I like you?” I felt blindsided by a loaded question, and immediately tried to interpret what she was getting at asking a question like that.

Me: “I don’t know.” I thought, *what a ridiculous question. Who cares whether you like me or not, what does it matter?*

Psychiatrist: “Seriously, do you think I like you or not?”

Me: “Does it really matter?”

Psychiatrist: “It matters to me.”

Me: “Well, probably not.”

Psychiatrist: “Why would you think I don’t like you?”

Me: “Well, I don’t know. I think I’m a bit of pain in the ass type of client. I come here and sometimes I don’t talk much, or don’t talk about things that maybe we should be talking about.”

Psychiatrist: “Well, I do, and I’m not paid to say that or to you like you, but I do like you. Every time you’ve left this office I’ve thought it would be the last time I’d see you, but you come back every week.”

Me: (Laughing) “Well, it’s hard. I don’t exactly like coming here because it’s hard.”

It was not knowing that the psychiatrist liked me that changed the nature of the therapeutic relationship and my level of engagement from this point onward. It was that she recognized how hard it was for me to show up every week, and the immense effort it took for me to show up week after week. For so long I felt like I was failing in my recovery; I spent so much time battling acceptance of having an eating disorder, constantly waivered between acceptance and denial, avoided discussion of internal distress feeding the eating disorder, and spent all my energy avoiding emotions. Where I had constantly felt like a failure in sessions, she identified that I was doing the work; I showed up. Our differences in opinion of the severity of my condition did not change; however, I learned that I did not need to hold the same opinion as her for her to appreciate how difficult this experience was for me and respect my limitations. From that moment on, the nature of what I was willing to explore and discuss in therapy drastically changed. I was able to identify that my inability to accept that I had an eating disorder and engage in conversation related to it stemmed from an immense amount of fear I had in that diagnosis, *what if it's true that this eating disorder is a coping mechanism and source of control? What if it's masking aspects of my life and emotions that are too painful to feel? If I don't know who I am now, what if I don't like the person I discover?*

Chapter IV: Recovery & Group Therapy

It is Going to Take More

Accepting that I had been afflicted with an eating disorder created space for me to explore and understand how it was infiltrating my life and destroying my sense of self. Despite my efforts to resist ED, the maladaptive thoughts and behaviours continued to evolve. Individual therapy was helpful in processing the immense internal battle I was facing daily, but it was not enough. Despite the maladaptive behaviours engrained in the eating disorder perpetuating internal chaos, it also served as an incredibly effective coping mechanism for all of life's challenges. It gave me the sense of control I needed whenever I was overwhelmed with life. If one speck of my life took an unexpected turn, I could turn to the eating disorder to regain a sense of control. ED would take over filling my mind, *I can't handle this, the last thing I need is to feel fat on top of it. Stop eating, stop preparing meals, stop meal planning. If you do this, you won't gain weight, you'll probably lose some, and you'll have more time to work on other things.* Focusing my efforts on the eating disorder disconnected me from the unbearable feelings that arose when something arose that was out of my control. In focusing my efforts on the eating disorder, I could ascertain that I would not gain any weight, preventing me from adding the 'feeling of fat' to the existing distress, and losing more weight would increase my self-confidence and be rewarded by external positive reinforcement.

My psychiatrist suggested I join a group therapy program based on a Dialectical Behaviour Therapy Model (DBT). She explained that this approach to therapy would be skills-based, giving me and opportunity to learn about and develop strategies pertaining to mindfulness, interpersonal skills, emotional regulation, and distress tolerance. In pursuit of knowledge and understanding around how my emotions, experience of distress, and coping

habits were interrelated with the eating disorder, I was eager to have an opportunity to further explore what was happening to me, and was ready to develop new, tangible ways of coping with life. I didn't understand why I was hurting myself and how I got to a point that I would punish myself for things that were not, logically or rationally, my fault. I wanted to learn how to tolerate distress without self-harming, and overall learn healthy ways to manage the pervasive, intrusive, negative thoughts that I was constantly overcome with. Originally developed as a treatment approach for Borderline Personality Disorder (Chen et al., 2015; Lynch & Cheavens, 2008). Due to its therapeutic approach of targeting problematic behaviours commonly associated with a multitude of psychological disorders, and its emphasis on emotional regulation DBT is considered a transdiagnostic treatment approach (Ritschel, Lim, & Stewart, 2015) that is helpful in treating eating disorders.

Internal Barriers to Accessing Treatment

The hope, excitement, and eagerness I had for joining group therapy was quickly met with ED's resistance, reminding me of the stigma that I would have to face in sharing with others that ED was destroying me from the inside out. The internal barriers to joining resided in my fear of facing the stigma associated with eating disorders, the shame I felt in having an eating disorder, and exposing the negative self-concept that was suffocating me. ED exclaims, *I haven't even told my family, friends, or doctors that I have an eating disorder. What if I know someone attending that group? What if I know one of the group facilitators? I don't look like I have a problem; people will think there's no reason for me to be there. What if I know someone in the group?* I had an extreme fear that exposing my psychological illness made me an unfit professional and would threaten my potential to live out my passions in life. I was worried that exposing the eating disorder would destroy all my hard work, efforts, accomplishments, and

expose me as phony. I felt shame invade me as I battled with ED on what attending this group would mean.

The shame came from feeling that my problems were not big enough, and my life was not terrible enough to be afflicted with an eating disorder. I did not feel I deserved the help, because I could not justify having an eating disorder. I knew that I was young, pretty, highly educated, had a loving family with limitless support, a wonderful co-parenting arrangement, and above all, I was the most blessed, fortunate, proud mother in the world. Having an eating disorder did not fit this picture of my life. The fear came from believing that the eating disorder threatened my professionalism, and aspirations of becoming a counsellor. From a young age, I aspired to work in mental health and help others build lives worth living and alleviate human suffering. According to Dimitropoulos et al. (2016)

Stigma has been internationally recognized as an important public health issue due to the significant psychological and social impairment experienced by individuals with mental illnesses and the economic costs incurred to society when the illness is concealed, or treatment delayed due to embarrassment and shame. (p.47)

The general public's misunderstanding and/or ignorance forming their perceptions of people with eating disorders as well as the causes and maintenance factors associated with disordered eating, significantly impact the stigma experienced by individuals with eating disorders (Williams, Russell-Mayhew, & Ireland, 2018). There was a war going on inside me, in which I constantly found myself fighting for who I was, going toe-toe with ED, exhausted by constantly resisting ED's intrusions. I was stigmatizing myself with my eating disorder. I didn't want anyone else to know what I was experiencing because I didn't have the fight in me to battle the external world with when I was already fighting war from within. From previous experience with

friends' perception of the eating disorder, I knew my experience would be discounted, minimalized, and trivialized leading to invalidation that would push me to retreat inside myself. I didn't want to feel defenseless. I didn't understand enough about the eating disorder to resist the stigma, and any attempts to defend my experience would only serve to distance the relationships I valued in my life. In their research on identifying how individuals with Anorexia Nervosa perceive public perception of this illness, Dimitropoulos et al. (2016) identified three themes: the view that Anorexia Nervosa is not an illness, it is an intentional illness (a choice if you will), and treatment is easy. Recipients of disclosures made by individuals with an eating disorder, significantly impacts the next steps an individual take regarding an eating disorder (Williams et al., 2018).

One day, upon walking into the women's washroom, I noticed a colleague wiping tears from their face. Upon asking if there was anything I could do, they began to share with me their experience with Depression, and on that particular day they were struggling with it. I was astonished at how open and honest someone whom I didn't know well, and who is in a highly reputable profession would be suffering with Depression. Their disclosure gave me an entirely new perspective on the stigma of eating disorders and the place of experiential knowledge within the mental health profession. It also brought to my attention the need to reframe my own perception of my struggles as they pertain to becoming a counsellor. I began noticing mental health challenges other professionals faced in their own lives. Realizing that my own opinion of professionals with psychological challenges didn't waiver helped me to reflect on how I viewed myself as a professional living with an eating disorder. I recognized that it didn't change my level of respect and confidence in them at all; in fact, it had the opposite effect. I sincerely respected and admired their openness and recognition of their challenges and fearlessness in

sharing these. I began viewing the courage to share within the community of mental health professionals as adaptive, healthy, courageous means of being true to themselves, and with this knowledge in the best position to serve their clients, through a heightened awareness of boundaries, transference, countertransference, overall reducing blind spots. It helped me to reframe how I perceived my relationship with the eating disorder. I realized that having an eating disorder did not discredit my professional abilities, and in my circumstances, made me much more effective in my career. I began appreciating aspects of the eating disorder that gave me insight into what it is like to be stigmatized, work through the stages of change, and barriers to accessing treatment. It gave me an opportunity to reframe my own experience living with an eating disorder as a mental health professional. I began recognizing how my experience with an eating disorder and the process of my recovery lead to immense personal and professional development that would make me an empathic, compassionate, effective, and confident counsellor.

Some of the most renowned psychologists, founders of major psychological theories and huge developments in the field, such as Carl Jung and Sigmund Freud, did so through the lens of challenges they experienced in their own lives (Alexander de Vos, Netten, & Noordenbos, 2016). Bringing awareness to the positive influences my own recovery could have on my clinical practice, also helped me to identify the challenges it could present. The difference this time, was that in reframing my experience with OSFED as an asset to my role as a counsellor, I was able to create space to explore the challenges with compassion, mindfulness, and encouragement. Bowlby, Anderson, Lewis, and Willingdon (2015) argued that professionals who had experiential knowledge of eating disorders “put great weight on internal changes in one’s sense of identity and attitudes toward that developing self”...and are...“better able engage in life with greater

appreciation than those who have not struggled, because of their recovery experience” (p.9). The road to understanding my role as a counsellor, who is also a human being with struggles, greatly increased my capacity of self-awareness, recognition of boundaries and countertransference, and the necessity to integrate mindfulness into my life. My experience reframing the meaning of being a professional with an illness, reduced my fears around stigma and allowed me to confidently accept group therapy as an additional treatment support.

Systemic Barriers

When I made the decision to commit to a group therapy and gave permission to the psychiatrist to pursue it, I was met with a major barrier- A one-year (maybe more) waitlist. I did not understand why it would take so long to get through a waitlist to receive treatment for conditions that are often life-threatening. I learned that DBT programs are incredibly expensive to attend, and if you are able to access one that is government-funded you have to live in that community and there is likely to be a long waitlist. I was frustrated, because I had gone through a lot to get to the decision of taking another step in my recovering and overcoming my internal barriers to accept group therapy as a treatment, only to find out that I may not ever be able to access it. A year seemed like a very long time to wait. I worried that life-changes during the wait, being forgotten or lost on the waitlist, or worse that the severity of the eating disorder would increase, preventing me from getting this treatment when space became available.

Studies indicate that individuals diagnosed with an eating disorder are significantly less likely to gain access to clinical treatment than those with other mental health illnesses (Innes, Clough, & Casey, 2017). Innes et al. (2017) suggest that individual characteristics including their attitudes and beliefs regarding treatment, socioenvironmental factor including availability of services and feasibility, and treatment-related factors including meeting criteria, location, and

treatment options are some of the main barriers individuals with eating disorders are met with in accessing clinical treatment. Furthermore, some of these challenges to accessing treatment vary depending on the type of eating disorder experienced (Thompson & Park, 2016). In their research on barriers to accessing treatment for eating disorders, Thompson and Park (2016) suggest that individuals diagnosed with OSFED are more likely to experience financial difficulties and individual barriers attributed to reluctance to disclose their illness to a physician, due to insurance coverage constraints that do not deem OSFED as a medically necessary illness for treatment coverage, and hindering disclosure due to lack of physical symptoms and fear of stigma.

Group Therapy

After a year on the waiting list, I was accepted into a DBT-based group therapy program. It consisted of three modules, each running for a duration of months in which I met weekly with the group, as I continued meeting weekly with my psychiatrist. The first module I started in was Emotional Regulation, followed by Distress Tolerance, and finally, Interpersonal Skills. Mindfulness skills were a fundamental skill taught at the beginning of each module, with the expectation that they would be utilized throughout the modules. According to Chen et al. (2015) the principle-driven (rather than agenda-driven) nature of DBT, supports therapists in flexibly addressing multiple and changing treatment targets (Chen et al., 2015). The structure of DBT created space where I could self-identify challenges and seek support from my treatment team as difficulties, I experienced evolved. With the complex nature of eating disorders involving varying degrees of maladaptive behaviours, distortions in cognitions, self-harming behaviour, desire for control, and acting as a coping mechanism in and of itself, it's emphasis on balancing change and acceptance strategies, focus on emotional dysregulation as a primary source of

psychological distress (Ritschel et al., 2015), and protocols for therapy interfering behaviours and crisis management (Chen et al., 2015) makes it an effective and useful approach to recovery of eating disorders. As treating eating disorders requires multifaceted approaches, DBT is an approach that is flexible, can easily be integrated with other therapeutic approaches, and materials can be adapted specifically for targeting behaviours ingrained in eating disorders (Chen et al., 2015; Ritschel et al., 2015).

Before the work on emotional regulation began, I spent three weeks learning about and being challenged to engage in a daily, seated, mindfulness practice. I thought, *Ugh! Not this again. Mindfulness is ridiculous. It's completely impractical. This is for hippies. Who wants to sit quietly in a room with a bunch of people? It's just so awkward and a waste of time.*

I had always viewed mindfulness and meditation as an activity that was flaky; something for people out of touch with reality and ultimately, not for me. In the first week of group therapy, my homework was to develop a seated mindfulness practice for five minutes a day. I went home, set up a little corner in my home with a yoga mat to sit on and candle, with the intention that this would become a family morning routine. For most of the week, I engage in the daily mindfulness practice as such, and felt proud to go back to group the next week and report my homework mastery. At the next group session, feeling proud, I shared my experience with the homework assigned. The feedback I received, brought to my attention that the homework was about me and not my family. Unable to tolerate the constructive criticism and observations, I felt defensiveness, self-criticism, and shame build up inside. ED declares, *you're a failure! You have no idea what you're doing; you completely missed the point. You're so stupid. Mindfulness is stupid! I hate mindfulness anyways and it doesn't do anything for me. Screw this!*

Feeling like a failure, and already disliking mindfulness practice I discarded it, yet again, as an unhelpful tool that was a waste of my time.

Previous work I had done with my psychiatrist led me to recognize how integral emotional processing was to the eating disorder. Learning what emotions were, how to recognize them, and develop adaptive ways of expressing and processing them greatly reduced the maladaptive and self-harming behaviours previously brought on by my inability to tolerate difficult emotions. I was incredibly invested in developing new strategies for managing emotions and tolerating distress, because what I was doing at that time wasn't working and was driving me further into disordered eating. I absorbed every piece of information that was given to me and I fully engaged. Of all the emotional regulation components I learned about, learning to prepare in advance, through the skill of coping ahead (Linehan, 2015) for situations I knew would evoke emotional distress was the trailhead that directed me on a path of self-discovery, self-compassion, acceptance, ultimately leading to a life of mindfulness that would (surprisingly) change my life. This strategy came to me in a time that I was anticipating the loss of a significant relationship in the near future. Learning to cope ahead is part of the skillset "ABC Please" (Linehan, 2015), which encourages the individual to accumulate positive emotions, build mastery of a skill, and cope ahead to reduce vulnerability to negative emotions (Linehan, 2015). I was determined to set myself up for successful emotional processing when I knew turmoil was insight. In learning to cope ahead, I was challenged to invest in finding and engaging in new activities to build mastery in. It was at this time, that I developed a passion for reading and love for being in bookstores. Entering bookstores, was like stepping into a realm of calm and stillness. I was enthralled with the knowledge that surrounded me, and the serene, gentle atmosphere that calmed any internal chaos I was experiencing. I grew up in chaos, lived a life of chaos, and was

surrounded by chaos at every bend in my life. I had never known what it felt like to experience a true, inner sense of peace and calm. I didn't know life could feel any different. Experiencing genuine relief of internal chaos, I was experiencing through a calming atmosphere and engagement with literature, I began exploring how I could create this in my daily life.

The passion I had developed for reading, and my existing values of growth and learning drew me to learning about mindfulness through books. I began reading about mindfulness and gratitude practice, and subsequently established a daily routine incorporating them into my life. I established a calming, mindful morning and evening routine that created a space for me to be me and recognize simple joys in life that I never attended to before. Every morning, I awoke to meditation music, had a mindful cup of coffee, lit my home with lamps and candles, had a mindful shower, and finally began a seated meditation practice before engaging with the rest of the world. I developed a similar routine for my evenings, which drastically increased my quality of sleep. In reflection, I don't believe I was creating a mindful practice; rather I was beginning to live a mindful life. I developed an affinity for a calm, peaceful home, something that had been foreign to me my entire life. Mindfulness lead me on a journey to understanding myself, who I was, my values, and how I wanted to live my life. It helped me to interrupt intrusive thoughts, better recognize me from ED, and greatly reduced distress I experienced at any given time. For the first time in my life, I was living my life for me and no longer for others; ED or otherwise.

Chapter IV: Summary, Implications, Conclusions

Summary

Eating disorders are biopsychosocial, life-threatening illnesses that are incredibly difficult to treat (Lynch et al., 2013) disproportionately affecting women in westernized cultures (Holmes, 2018). The multifactorial challenges inherent in them, including internal cognitive distortions, emotional dysregulation, and maladaptive behaviours, necessitate implementing multi-dimensional approaches to treatment (Holmes, 2018). My research presents first-hand accounts of these challenges, through an exploration of lived experience with OSFED-Atypical Anorexia. The presentation and recovery experienced living with an eating disorder is an individual experience that varies from person to person, in which individual barriers account for some of the challenges in developing a consistently effective treatment agreed upon by researchers for eating disorders (Thompson & Park, 2016).

Unique circumstances grounded in the pre-existing condition of a chronic kidney disease and its effect on my own experience with disordered, aligns with current research findings on treatment through individual-factors ingrained in the experience of the eating disorder and integrating different treatment methods to address the individual difficulties inherent in one's experience. This paper explores treatment through experience with weekly individual therapy, and participation in a nine-month Dialectical Behaviour Therapy program.

I chose to address disordered eating and the interplay of chronic illness through an evocative/narrative autoethnography approach, to connect to both mental health professionals assisting with client-recovery, those who are suffering with disordered eating, and appeal to the need for society to take an active role in recognizing and resisting eating disorders through

recognizing the significant impact of westernized culture's discourse in the prevalence of disordered eating practices. McCormick (2018) writes

Autoethnography allows deeply personal experiences to be portrayed and considered in wider cultural contexts so that they can be probed for significances and meanings that are of value to others. (p.268).

The significance of this study is to help readers better understand disordered eating practices, the cultural implications and impact on westernized society, in the hopes of changing attitudes, reducing stigma, and inspiring societal engagement in acts of resistances to the pervasive issue of disordered eating in westernized culture. I believe that when we courageously connect personal experience with research, we can facilitate open conversation, deeper connections, and collective support on sensitive issues negatively impacting westernized society. In approaching this research as an autoethnography, I was able to find meaning in my suffering, that I hope resonates with readers who take up position on the battlefield and courageously engaged in resistance against disordered eating. It allowed me to better understand who I am, where my values lie, and to recognize and validate every ounce of resistance to a cultural-ingrained problem that afflicted me on a personal level. Narrative approaches of reframing, recognizing these acts of resistance, and separating myself from ED in conjunction with the psychoeducation helped me to better understand the personal and cultural problems related to eating disorders.

Finally, presenting research on the issues enveloped in disordered eating through an autoethnography approach, has challenged me to reflect and actively engage in finding personal meaning, growth, and value.

Implications

The complexities and suffering that make eating disorders incredibly challenging to treat are hidden in that which cannot be seen. It is the war experienced within oneself that pervasively seeks to torment and damage self-concept. The severity of an illness is often judged by the visibility of the ailment; however, this autoethnography addresses the toxicity and pervasive internal battle that one is called to take of a resistance against. By asking, “what is going on below the surface?” we can create space for the issues to come forth and tangibly recognize, understand, and deal with them. When the problem continues to be buried inside a secret of shame and self-hatred, covered by control and perfectionism the problem becomes an internal battlefield that an individual suffering with an eating disorder is standing alone on a battlefield, outnumbered by forces and fighting for their life. It takes a community, family, friends, and shifts in cultural discourse to take a position on the battlefield and give someone a fighting chance. It requires that, as a society, we inquire on our position and connection to disordered eating practices. My hope is that the content of this autoethnography creates a deep connection with each reader, regardless of their position; from doctors and mental health professionals, to family, friends, and communities, each one has its own link to disordered practices whether it be direct or indirect. My initiative has been to encourage connection through revealing the secrets that bury them and maintain their invisibility, perpetuating and execrating isolation.

This research is helpful to doctors and specialists treating patients with chronic illnesses in recognizing the possibility of links between management behaviour of a physical illness and predisposition for development of an eating disorder. Doctors who take the time to recognize the impact of dietary restrictions, weight fluctuations, and other relevant factors of a chronic illness that can threaten body image may be able to help patients access additional supports that could

be helpful in preventing secondary illnesses, such as eating disorders. Early detection of eating disorders, significantly impacts outcomes of eating disorder treatments, in which doctors who are in a primary care role and have insight into patients' current medical challenges have the ability to monitor and increase awareness of the potential threat to development of eating disorders if aware of the factors within current medical challenges that could impact the onset of disordered eating (Rowe, 2017).

Another implication of this research lies in the impact that educating counsellors, friends, and family can have in responding to eating disorders from a place of empathy, non-judgement, and openness. Stigmatizing attitudes and beliefs about eating disorders impact responsiveness to the issue, affecting the well-being, disclosure, and treatment seeking of individuals battling disordered eating (Innes et al., 2017). By increasing knowledge of the complexities ingrained in eating disorders, I hope that this research will help to increase supportive responses of those that are entrusted with a disclosure of eating disorders. The way in which we respond directly and indirectly to eating disorders, significantly affects the trajectory of help-seeking behaviour and access to treatment in persons afflicted with disordered eating (Dimitropoulos et al., 2016).

I also hope this autoethnography reaches out to warriors who take up resistance against their own eating disorder. That it instills a sense of perseverance and necessity of building an army of support that encourages resiliency to maladaptive behaviours that perpetuate eating disorder behaviours.

Limitations

Inherent in the nature of autoethnography writing are limitations regarding generalizability and ethics. As this autoethnography focuses on eating disorders through the lens of OSFED intertwined with chronic illness, the nature of meeting criteria for OSFED and the

unique nature of the implications of a preexisting chronic illness, this study is not generalizable to other forms of eating disorders. Although my illness is most similarly related to Anorexia Nervosa, there are criteria such as not meeting underweight criteria that often contributes to other physical challenges, requiring different or more inclusive treatment procedures related to this. In regards to ethics, time frames, connections, and certain interactions pertaining to relationships to me needed to be altered. Information regarding family and child trauma were completely omitted due to ethical concerns and the necessity of maintaining integrity and protecting the well-being of my family. As childhood trauma is recognized in literature as a prominent predisposition to the development of an eating disorder, this information would have been more helpful in giving context and background information to the issue of predisposition and onset of the eating disorder and provide a more thorough understanding of the repercussions to emotional regulation, perfectionism, and need for control which were significant factors driving the eating disorder.

Exploration of treatment methods addressed were limited to Dialectical Behaviour Therapy and individual therapy with a psychiatrist. Furthermore, the treatment reflects accessing as an outpatient, and does not explore treatment as an inpatient or account for the nature of the different services that are more typical of inpatient services. In addition, the paper highlights the implications of living in a patriarchal society dominated by male discourse, and the cultural effect is having on women living with an eating disorder. Men are also afflicted with eating disorders, with current research literature positing that due to cultural norms and expectations of men that they are less likely to report or seek treatment and may experience disordered eating in different ways than women.

I feel it necessary that I acknowledge my privilege of education in psychology and access to support and treatment due to an already existing interdisciplinary team of doctors of mental health professionals consisting of a nephrology specialist, nurse, dietician, pharmacologist, and social worker. Therefore; my ability to self-identify an issue and obtain the necessary supports for treatment is unique to my individual situation. This accessibility, combined with exacerbated concern of the effect on my kidney condition, lead to early identification of the eating disorder and efficient Treatment, comparatively to the average access to treatment of eating disorders being ten to fifteen years after onset (Innes et al., 2017). It is likely that this early detection and treatment was a factor contributing to positive recovery outcomes.

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Appendix A: Consent Letter for Research Participants.

Dear _____ ,

As informed, you are aware that I am a student currently completing a Master of Counselling with City University in Canada. As such, I am required to write a thesis as part of the graduation requirements. I have chosen to use Auto-Ethnography research in "Exploring the Complexities and Connections of Disordered Eating and Chronic Illness."

Through auto-ethnographic research, I will engage in how my experience with chronic illness, affect, and coping are intertwined with my personal experience living with an eating disorder. To do this, I will be reflecting on the trajectory that the eating disorder took through my account of childhood memories and development, journal writings, photographs, engagement with psychiatry appointments, and participation in a DBT-focused program. As elements of this involve family and close connections, with your permission, there is a possibility that you may be included. I will be approaching this method with great care. If any direct quotes pertain to you, I will consult with you before-hand with the specific quote and only include if acceptable to you. The identities of any family and friends will not be revealed (no names will be included). In Addition, you will be notified if information pertains to you and have the opportunity to review and approve, reject, or edit it.

Although your name would not be explicitly identified in my research, there may be circumstances in which I will refer to my relationship to you; as such, it may be possible for you to be identified by the nature of this relationship. For example, I may mention, "my mother" or "my family" in which case it is possible that the identified connection would indicate your identity. After completion of this thesis, it is possible that it would be available online; in which case you could potentially be identified by the reader(s).

I want to ascertain that, given the above information regarding identity, you are comfortable in the circumstances that you may be included in my thesis and could be identified by your inclusion in "family" and/or by your relationship to me, "mother." If this is something you are not comfortable with, please inform me and I will not include any information in which you could potentially be identified.

Participation in my research is confidential and voluntary. In order to make sure you are comfortable with the capacity to which you are mentioned and involved in my research, I will provide you with a copy of my thesis once it is complete. If there are any areas of the research in which you are uncomfortable with, I will edit the specified issues and provide you with a revised copy for further review. Should you choose to give consent, you have the right to withdraw it at any point without negative consequences.

If you consent to potentially being mentioned in my research, all information associated with you will be kept secure and confidential in my personal, password protected computer.

Sincerely,
Jodie Read

Participant Signature: _____

Appendix B: Institutional Review Board Certificate of Approval

Institutional Review Board**Certificate of Approval****IRB ID# Read_Stella101618**

Principal Investigator (if faculty research):

Student Researcher: Jodie Read

Faculty Advisor: Maria Stella

Department: DAS M couns.

Title: Exploring emotions and functionality of EDNOS

Approved on: October 16, 2018

Renewal Date: October 16, 2019

- Full Board Review
- Expedited Review (US)
- Delegated Review (Can)
- Exempt (US)

CERTIFICATION

City University of Seattle has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The Faculty Advisor Maria Stella and the student researcher Jodie Read have the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original Ethical Review

Protocol submitted for ethics review. This ***Certificate of Approval*** is valid for the above time period provided there is no change in experimental protocol, consent process, or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair of the Institutional Review Board in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the IRB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion.

A handwritten signature in black ink that reads "Brian Guthrie". The signature is written in a cursive, slightly slanted style.

Brian Guthrie Ph D, RSW, RCSW
Chair, IRB City University of Seattle