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Coming into Focus: Parents' Experiences of Discovering their Child has Anorexia Nervosa

by

Emily Pauline Williams

A THESIS

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Abstract

After witnessing from both up close and afar how different families can respond to learning that their child is sick, and most likely has an eating disorder, I became deeply curious about the nuances in these parents' reactions. I wondered about why some parents take fast action in helping their children, while others seem complacent or hesitant to recognize or admit that anything troublesome is happening. These curiosities propelled me into this research, where I sought to better understand how parents discover that their child has anorexia nervosa.

My aim for this philosophical hermeneutic inquiry was to speak to parents who had discovered that their child was or had been experiencing anorexia nervosa. I interviewed 12 parents, making up nine families with a child with anorexia nervosa and asked about their discovery experiences. Findings from interviews and analysis revealed that discovering one's child has/had anorexia nervosa was incredibly complex. Parents' experiences illustrated that they were fractured by the discovery and by the illness, questioning their competencies and actions as parents. It was evident that the discovery was a continuous, ambiguous process, and at times information was both revealed and concealed from parents. Finally, interviews exposed the unspeakable nature of anorexia nervosa, and ways parents coped with the devastating impacts that anorexia nervosa had on their child, their family, and themselves.

I conclude with implications for both research and clinical practice, where I make a case for greater supports being made available for parents during these chaotic and ambiguous times. Every parent that I interviewed shared that they felt left in the dark, without basic information regarding their child's current status and possible prognosis. Parents felt unsure of how their lives had and were about to change, understandably, feeling enormous pressures and confusion as to how to support and care for their child with anorexia nervosa. While the child with

anorexia nervosa is the fundamental focus, parents are worthy and in fact desperate for special attention as well.

Keywords: discovery, disclosure, anorexia nervosa, hermeneutics, parents

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Dedication

To the 17-year-old who fought with her dad in the narrow streets of Venice, Italy. You have come so far.

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List of Abbreviations

AN	Anorexia nervosa
BN	Bulimia nervosa
BED	Binge eating disorder
DSM	Diagnostic and Statistical Manual for Mental Disorders
ED(s)	Eating disorder(s)

Chapter One: Introduction

Eating disorders (EDs) encapsulate a broad range of cognitions, behaviours, signs, and symptoms related to eating and food disturbances. Individuals with EDs experience a heterogenous cluster of manifestations including dietary restraint, low weight, starvation, overvaluation of the body, binge eating, purging behaviours, being overweight, and food refusal based on sensory aversion (Murray, 2019). While great diversity exists in ED presentation, several classifications have been created in order to categorize individuals based on symptom phenotypes. The Diagnostic and Statistical Manual for Mental Disorders (DSM – 5) lists the following classifications of EDs: avoidant/restrictive food intake disorder (ARFID), anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), otherwise specified feeding or eating disorder, and unspecified feeding or eating disorder (American Psychiatric Association [APA] 2013). Each classification of ED represents a unique cluster of symptoms, characterized by a persistent disturbance of eating or eating-related behaviours that significantly impairs physical health or psychosocial functioning (APA, 2013). The DSM – 5 specifies that the diagnostic criteria for ARFID, AN, BN, and BED result in a categorization scheme that is mutually exclusive, meaning that during a single episode, only one of these diagnoses can be assigned (APA, 2013). The reasoning behind this classification system is that although these presentations share some features, they differ significantly in clinical course, outcome, and treatment requirements (APA, 2013).

Eating disorders are the costliest of all psychiatric disorders to treat (Bardach et al., 2014), and AN specifically is one of most destructive psychiatric disorders, with mortality rates six times higher compared to the general population, and crude mortality rates between 5 and 9% (Arcelus, Mitchell, Wales, & Nielsen, 2011; Berkman et al., 2007). Among individuals who

survive and live with AN, the common course of illness is chronic and relapsing (Murray, Loeb, & Le Grange, 2018). Over the past decade countless researchers and clinicians have studied ED etiology, risk and protective factors, course and maintaining factors, treatment effectiveness and efficacy, medical complications, recovery rates, and prevention strategies. Despite the comprehensive research that has been conducted, current evidence demonstrates that the majority of individuals with EDs do not fully recover during treatment (Murray, 2019). Studies examining treatment-seeking populations have demonstrated that 23-33% of adolescents with AN reached remission by the end of treatment (Le Grange et al., 2016; Lock et al., 2010), of which approximately one third remained in remission at 4-year follow up (Le Grange et al., 2014). More recently, Lock and Le Grange (2018) suggested that the leading evidence-based psychological treatments for AN typically result in one third of individuals reaching full symptom remission by the end of treatment, while one third of those maintain symptom remission at long-term follow up. These findings highlight the significance for continued improvement efforts for ED prevention and treatment. As the field continues to examine factors that can optimize outcomes, some foundational elements related to EDs continue to go unstudied, one of those gaps being the disclosure and/or discovery of EDs. Though there are multiple classifications of EDs, all deserving of continued research and funding, the current study focuses on the presentation of AN.

Discovery

Little is known about how AN is "discovered" in those living with it. Discovery can be conceptualized in several ways, the first being intentional disclosure to others, and the second being through unintentional signs or behaviours that reveal the problem. Given the complexity

of AN and the process of discovery, the research question guiding this study is: *How might we understand the experiences of parents who have discovered they have a child living with AN?*

Anorexia nervosa it is riddled with complexity and ambiguity (Ryan & Callaghan, 2014; Williams & Reid, 2010; Williams, Russell-Mayhew, Moules, & Dimitropoulos, 2018). Throughout the course of AN, ambiguity is not far away, but rather is a hallmark of the experience (Williams et al., 2018). This ambiguity is evidenced through (a) the ambivalence often reported towards AN and motivations regarding recovery (Nordbø, Espeset, Gulliksen, Skårderud, Geller, & Holte, 2012); (b) the complicated recognition process and frequent denial of symptoms (Gray, Murray, & Eddy, 2015), and (c) the inconsistent outcomes for those with AN (Byrne et al., 2017). For a more thorough understanding of the ambiguity inherent during all phases of AN, refer to Appendix A, where I present an earlier publication on the topic.

The process of discovery makes the issue of AN even more complex. Individuals struggling with EDs (i.e., AN, BN, BED, other specified feeding or ED) are often hesitant to disclose they have a problem (Becker, Grinspoon, Kilbanski, & Herzog, 1999). Although not a lot is known about this disclosure process, individuals with EDs tend to score lower on measures of self-disclosure (i.e., the Self Disclosure Questionnaire) compared to individuals not experiencing disordered eating (Le Grange, Tibbs, & Selibowitz, 1995). The reasons for this difference remain unknown. Several research teams have produced evidence suggesting that individuals engaging in various types of disordered eating who experience negative body image are less likely to share experiences related to eating and weight compared to participants not concerned with these issues (Le Grange et al., 1995). Further, secrecy and concealment are behaviours typical of individuals with AN as evidenced by clinician reports (Basile, 2004). In addition to the difficulty experienced by clinicians, researchers studying AN have indicated that

individuals' denial in illness is a complex factor that remains obscure (Starzomska, & Tadeusiewicz, 2016). Adding to the complexity, there is no common agreement between researchers as to the reason for denial (Starzomska, & Tadeusiewicz, 2016). Whether denial in illness is intentional or not, researchers have been left struggling with how to effectively collect accurate information from this population in order to best serve them.

Based on available literature, there are various reasons individuals experiencing EDs are either not likely to share their experiences with others, or present as hesitant to do so (Becker et al., 1999). Based upon these limited findings, and in combination with reports regarding high levels of secrecy, denial about symptoms, and minimization that anything is wrong (Gray et al., 2015; Muscari, 2002), it is not surprising that many individuals with AN experience ambivalence towards disclosing they have a problem. In addition, many remain silent in order to maintain their weight loss and sense of control (Williams et al., 2018). These factors additionally contribute to this complex problem.

Though not all details are understood about the disclosure experience, Williams, Russell-Mayhew and Ireland (2018) have suggested that the experience of disclosure is a process extending over time and involves multiple interactions with others, not a one-time event. Further, many individuals with EDs feel they can no longer hide from others, feeling "too far gone" to continue to conceal their behaviours (Williams et al., 2018). Disclosure is complex and unique for each individual, and the target of disclosure is a major component of the interaction (Williams et al., 2018). Family members and friends are cited as the most likely recipients of disclosure (Becker et al., 2005), however little is known about family members' experiences of these emotionally charged interactions. To add to the complexity already at play, families may discover that their loved one has been experiencing AN with or without that individual choosing

to come forward with this information. Therefore, whether the AN is learned through a planned disclosure or through an unintentional discovery, the situation can quickly become heightened, making the experience of discovery a critical moment in the lives of the family members and the individual affected by AN.

Families caring for individuals with EDs report high levels of stress and burden (Gisladottir et al., 2017; Quong & Chen, 2018; Treasure et al., 2008; Zabala, Macdonald, & Treasure, 2009). Further, the expressed emotions (e.g., criticism, hostility, positive statements) of caregivers can delay the recovery for individuals with AN (Gisladottir et al., 2017; Zabala et al., 2009). Families play a vital role in supporting loved ones with EDs, particularly in the recovery process (Treasure et al., 2007; Treasure et al., 2008; Uehara, Kawashima, Goto, Tasaki, & Someya, 2001).

Overview of Research Design

The concept of discovery is used as an umbrella term to capture both planned disclosure and the unplanned experiences where individuals find out that a member of the family is experiencing AN unbeknownst to them. Using this term to capture the experience I seek to better understand is fitting, given that *discovery*, means to "obtain sight or knowledge of for the first time" (Merriam-Webster, n.d.). First used in the 1300s, *discover* meant to "divulge, reveal, disclose" (Online Etymology Dictionary, n.d.). The term suggests an undertone of disloyalty, that can be traced back to the Old French term *descovrir* meaning to "uncover, unroof, unveil, reveal, betray" and from the Late Latin *discooperire*, *dis*- translating to "opposite of" and -*cooperire* meaning "to cover up". In the 1550s, discoverer originally meant "informant" (Online Etymology Dictionary, n.d.), hence the etymology is reflective of the experience of one's AN being discovered by others, whether this was intentional or not.

Why this research? Research about the experiences of recipients who discover their loved one is living with AN has never been conducted and represents a gap in the literature. To confirm this, a subject librarian was consulted. The following terms were entered into PsycINFO, CINAHL, and EMBASE databases: disclosure, self-disclosure, discovery, anorexia, anorexia nervosa, bulimia, bulimia nervosa, eating disorder, eating disorders, disordered eating, family, and family interaction. The database search produced no results that matched the current study. In addition to this research being novel, among the limited literature available examining discovery experiences of those with EDs in general (including both BN and AN; Becker et al., 2005; Gilbert et al., 1995; Williams et al., 2018), the voices of family members are missing in our understanding of the discovery process. Discovery might be comprised of a process of stress, fights, and high emotionality building up over time or conversely be a complete surprise to the recipient of discovery. For some with AN, the decreasing size of the body may be difficult to conceal from others. For these individuals, it may feel like it is only a matter of time before others' suspicions turn into probing comments and/or high stress situations. Individuals with AN, particularly adolescents or children living within the family home, are especially likely to have been on the receiving end of family suspicion or tension leading up to the discovery or confirmation one has been struggling.

Since families are heavily relied on as support systems for individuals with AN (Blondin, Meilleur, Taddeo, & Frappier, 2019; Gisladottir et al., 2017; Quong & Chen, 2018), it is imperative that more be known about this dynamic, relational discovery process. When such discoveries are made, parents play a vital role in the development and functioning of the family's response to the situation.

Concluding Thoughts

The central focus of this work revolves around parent's experiences of discovery, and parallel to that, I too am on a discovery mission of my own. In the following chapters, I offer a review of relevant literature and describe hermeneutic inquiry as the method and philosophy guiding this exploration of the unknown. I then offer a findings section comprised of several distinct chapters on discovery, including the fracturing capacity of AN, aletheia: revealing and concealing, and the unspeakable nature of EDs. I then present an integrative chapter tying my interpretations back to the topic as a whole, and conclude with implications for both clinical practice and future research.

Chapter Two: Literature Review

This research is the first to examine the experiences of parents discovering that their child has AN. Though literature on the topic of discovery and AN is limited, research has indicated that when one discloses a mental illness (e.g., depression, anxiety) to others that they feel as if they are "walking on eggshells" afterwards (Lakeman et al., 2012). This reference to being uncomfortable after a disclosure is also reflected in strained relationships occurring with the recipients of disclosure after the disclosure has been made (Treasure et al., 2001; Kyriacou et al., 2008). Though these findings are not specific to EDs or AN, other literature supports that AN, in particular, is a disorder that produces a salient social impact on others, negatively influencing the quality of life of family members (Gisladottir et al., 2017; Quong & Chen, 2018; Zabala et al., 2009). In this chapter, I present a review of the literature relevant to the topic of parents discovering AN, including, AN's history and medical conceptualization, risk factors and etiology models of AN, illness trajectory and prognosis, how families have historically been viewed in the causation of EDs, parental influences on the development and maintenance of AN, differences in reactions between mothers and fathers, and parental involvement and consequences.

Anorexia Nervosa

According to the DSM – 5, three criteria comprise the symptom presentation of AN:

> a) restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health, b) intense fear of gaining weight or of becoming fat, or persistent behavior that interferes with weight gain, and c) disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on

> self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight. (APA, 2013, pp. 338-339)

In addition, two subtypes exist: restricting type and binge-eating/purging type. Restricting type refers to individuals who during the past three months, have not engaged in re-current episodes of binge eating or purging behaviours. In this subtype, weight loss is achieved through restrictive eating, primarily through dieting, fasting and/or excessive exercise. For individuals classified with binge-eating/purging type, during the past three months, these individuals have engaged in recurrent episodes of binge-eating and purging (APA, 2013). Regardless of subtype, losing a significant amount of one's body weight is a hallmark feature of AN (Gray et al., 2015). According to Micali, Hagberg, Petersen, and Treasure (2013), most individuals with AN present to treatment at the age of 16, and other literature has demonstrated the mean duration of illness is 6-7 years (Stoving, Andries, Brixen, Bilenberg, & Horder, 2011).

In addition to the diagnostic criteria, clinicians working with this population look for other features to inform their conceptualizations. Namely in children or adolescents, a failure to reach expected height trajectory can be observed, instead of weight loss. In addition, individuals experiencing AN typically display a fear of weight gain or becoming fat, yet as more weight is lost these fears do not dissipate and can even increase. Further, related to criterion C, individuals may either believe they are globally overweight, or might be preoccupied with certain parts of the body, such as perceiving their legs or stomach as fat. The self-esteem of individuals with AN is highly dependent on the perceptions of one's body size and shape, and weight loss is considered an achievement and marks those that are self-disciplined. Conversely, weight gain is hugely disappointing and a mark of unacceptable self-control. Lastly, though some with AN

recognize their bodies as becoming too thin, very seldomly will they acknowledge the critical medical complications and implications of their starved state (APA, 2013).

Risk and Environmental Factors

In addition to describing the diagnostic criteria for AN, it is helpful to understand risk and prognostic factors that can contribute to the development of AN. As Striegel-Moore and Bulik stated, "A risk factor is a characteristic (e.g., allele), event (e.g., teasing), or experience (e.g., growing up in a culture that values extreme thinness) that precedes the onset of the outcome of interest (e.g., an eating disorder)" (2007, p. 183). Thousands of articles, books, and chapters have attempted to determine the causes of EDs. The current consensus for ED etiology is the "biopsychosocial" model (Frank, 2016; Polivy & Herman, 2002; Rodgers, Paxton, & McLean, 2014). The advantage of this model is that it conceptualizes etiology broadly, suggesting that many factors including cultural, biological, familial, social, personality, and learning, to name a few, all contribute to the development of EDs. The disadvantage of the model is the lack of specificity.

Sociocultural influences. Eating disorders do not occur uniformly across all geographic locations; in fact, EDs occur more frequently throughout cultures that place an emphasis on thinness (Polivy & Herman, 2002). Cultures privileging thinness as an ideal body shape typically have an abundance of food available to them. Conversely, cultures with food scarcity often idealize more rounded bodies, suggesting that across cultures bodies that are difficult to achieve given the availability of food are idealized (Polivy & Herman, 2002). According to cultural models of EDs, the following steps occur and lead to the development of EDs: exposure to the thin ideal, internalization of the thin ideal, and experiencing a discrepancy between the thin ideal and the self (Striegel-Moore & Bulik, 2007). Further, individuals living in cultures or

participating in activities/settings that value thinness (i.e., competitive dancers, models, elite athletes) are at increased risk (APA, 2013). Thus, external factors, such as settings in which individuals are raised and work contribute to risk for AN.

Next, there is a gendered aspect to ED risk, such that epidemiological research demonstrates that EDs are more common among females than males (Hoek, 2006; Striegel-Moore, 1997; Striegel-Moore & Bulik, 2007). The single best predictor of an ED is being female (Striegel-Moore & Bulik, 2007). As a result of the glorification of thinness and demonization of fatness in cultures of abundance, many females report dissatisfaction with their bodies. This is an important risk factor to be aware of, as literature repeatedly demonstrates that body dissatisfaction is a critical risk factor for the development and maintenance of EDs (Polivy & Herman, 2002; Stice & Desjardins, 2018). The more intense one's body dissatisfaction, the more likely one is to engage in practices to lose weight.

Biological influences. Twin and family studies have uncovered a genetic component to EDs, namely that there is a tenfold increased genetic risk (Strober, Freeman, & Lampert, 2000). Family studies have demonstrated that there is a strong genetic component to the heritability of AN (Grice et al., 2003). In the first genome wide linkage analysis (underscoring the importance of phenotypes), families with at least one relative presenting with non-specified ED symptoms were analyzed. In this general sample, no signals of interest across genomes were detected, however, when restricting the sample to individuals presenting with AN restrictive subtype, Grice and colleagues (2003) found the presence of an AN-susceptibility locus on chromosome 1p, which demonstrated a susceptibility gene for AN. This highlights the relative importance of strictly genetic factors. Further, various research teams have determined that 48% (Kortegaard, Hoerder, Joergensen,Gillberg, & Kyvik, 2001), 58% (Wade, Bulik, Neale, & Kendler, 2000), and

76% (Klump, Miller, Keel, McGue, & Iacono, 2001) variance in AN are attributed to genetic estimates. Finally, EDs have also received attention from an addiction perspective. Davis and Claridge (1998) proposed the addictions model of EDs, that posits that individuals with AN may be addicted to endogenous opioids, which are released during self-starvation and accompanied by exercise. Further, theories conceptualizing EDs as substance-based food addictions (Schulte, Potenza, & Gearhardt, 2017) and behavioural eating addictions (Hebebrand et al., 2014) have been debated within the field.

Individual influences. Literature shows that various factors related to the individual, whether located within the individual or an event that occurred to the individual contribute to the development of EDs. Personality traits including obsessive-compulsiveness, rigidity, perfectionism, and need for control all increase the risk of developing AN, and have been found during childhood, after recovery, and in relatives of individuals impacted by AN (Anderluh, Tchanturia, & Rabe-Hesketh, 2003; Sutandar-Pinnock, Blake, & Carter, 2003). Further, Woerwag-Meht and Treasure (2008) reported that harm avoidance, low novelty seeking, and low cooperativeness have been traits found in individuals with AN, demonstrating how these traits can also interfere with treatment and recovery. In the following section, I trace the history of AN, considering how the disorder has evolved throughout the century and how this evolution is conceptualized today.

History of Anorexia Nervosa: The Hysterical Female

Broken down, the prefix *an* translates to "without" and *orexis* means "appetite," therefore in full translating into "lack of appetite" (Merriam-Webster, n.d.). The history of the conceptualization of AN is full of fascination and allure specific to the era, adding obscurity to the term's construction by medical professionals of the last several centuries. Researchers

examining the archives of hospitals and mental asylums from the 16th to 19th centuries established notable accounts of fasting women and varied explanations of the disorder (Habermas, 2015; Parry-Jones, 1985).

The varied conceptualizations seem to be due to nationality and era. French physician Lasègue introduced the term *anorexie hystérique* in 1873, and one year later the term *anorexia nervosa* was coined by British physician, Gull in 1874 (Habermas, 2015). Differences in conceptualizations stemmed from the French tradition of paying greater attention to psychological aspects of the condition, whereas British traditions emphasized the physical and behavioural features (Habermas, 2015).

French conceptualization. French physician, Lasègue described the condition in terms of hysteria, noting that his female patients had afflictions of the mind, suffering from "some emotion which she avows or conceals" (1873/1997, p. 493). Lasègue described the syndrome eventually becoming the sole object of preoccupation and portrayed his patients with AN as hysterical:

> What dominates in the mental condition of the hysterical patient is, above all, the state of quietude-I might almost say a condition of contentment truly pathological. Not only does she not sigh for recovery, but she is not ill-pleased with her condition, notwithstanding all the unpleasantness it is attended with. In comparing this satisfied assurance to the obstinacy of the insane, I do not think I am going too far. (p. 495)

British conceptualization. In 1874 (adapted and reprinted in 1997), Gull published a piece on a peculiar condition characterized by extreme emaciation, which he referred to a disease that occurred mostly in young females. Gull used phrases such as "complete anorexia for animal food, and almost complete anorexia for everything else" (p. 498) in his description of a former

patient. In addition to describing his patients' physical states in his case studies, Gull made bold remarks regarding the treatment and lack of consideration of the patient's desires in their treatment. He made clear the dangers of continued starvation and noted that "the inclination of the patient must be in no way consulted" (p. 500). Further, Gull spoke to the destructive mental states of the women he treated, referring to young females being "specifically obnoxious to mental perversity" (p. 501) and females with this syndrome not being of sound mind to make their own choices about caloric consumption.

Since the time of these physicians' early writings of AN, others have gone beyond descriptions of lack of appetite and hysteria by describing distinctive features such as addiction to extreme thinness, referred to as a "drive towards emaciation" (Selvini Palazzoli, 1963/1974), relentless pursuits of thinness (Bruch, 1965), and having a "morbid fear of being fat" (Russell, 1970). Clearly, the evolution of these descriptors throughout the 19th and 20th century point to how AN has been disputed throughout history, and how many of these disputes continue in present among medical and mental health professionals.

Our understanding of AN has evolved over time. As more is understood about the development and trajectory of AN, the conceptualization will be modified to meet the time period and be congruent with modern practices and theory. Regardless of this changing and ambiguous identification process for what constitutes AN, questions still remain: What happens next for someone with AN? How do they experience AN?

Ambivalence to One's Experiences of Anorexia Nervosa

Not only is the history of AN marked with contestation, but so is the experience of living with the disorder including one's will to recover and autonomous motivations regarding AN (Nordbø et al., 2012). Anorexia nervosa is considered to involve greater ambiguity and

ambivalence compared to other EDs (e.g., BN, BED), and individuals with AN tend to appreciate their symptoms differently than other groups experiencing mental illness (Nordbø, Espeset, Gulliksen, Skårderud, & Holte, 2006). Egosyntonic, referring to states, thoughts, behaviours, or feelings that are congruent with one's self-concept, and ambivalence are central features of AN (Marzola, Abbate-Daga, Gramaglia, Amianto, & Fassino, 2015). According to qualitative inquiries, some individuals have little desire to make changes, as AN is a source of pride and endurance that provides a sense of achievement and self-confidence (Nordbø et al., 2006; Robinson, Kukucska, Guidetti, & Leavey, 2015). Further, researchers have illustrated how individuals with AN often depict their AN as providing them with a sense of security and stability, a way to avoid negative experiences, and as a way of obtaining a sense of power and inner sense of mastery and strength (Nordbø et al., 2006). At the same time, there are also individuals who are ambivalent about the disorder, not sure whether the AN controls them or whether they are in control of it, and irresolute if they wish to recover or maintain it (Colton & Pistrang, 2004; Reid, Burr, Williams, & Hammersley, 2008; Williams & Reid, 2010). Some individuals with AN regard their symptoms as a set of behaviours that are meaningful and positive in their lives (Nordbø et al., 2006), whereas others are ambivalent, only at times wishing to rid themselves of their restrictive eating behaviours and/or weight loss routines and resume the life they once lived (Williams & Reid, 2010). In addition, others with AN may have different experiences entirely, emphasizing the heterogeneity of how one perceives their symptoms and the impact on their life. Much like the ambivalence regarding one's feelings toward their AN, individuals also vary in how they wish to proceed in the course of their experience with AN. Some may decide to disclose and ask for help, whereas others might not. Evidently, the experience of AN is individual and widely varied, and as such an ambiguous quality emerges.

Ambiguity of Anorexia Nervosa Recognition and/or Diagnosis

After a discovery, sometimes a long, complicated, and ambiguous process of recognition and assessment follows. Factors contributing to this process include differentiating between other medical conditions and symptoms mimicking malnourishment (Schwarz, Ponder, & Feller, 2009), late-onset EDs (Santonastaso, Camporese, Caregaro, & Favaro, 2008), and atypical cases (APA, 2013; Forney, Brown, Holland-Carter, Kennedy, & Keel, 2017). Further, symptom presentation varies and is as heterogeneous as the group of individuals AN affects. For example, in some individuals, as the illness becomes more severe and weight is lost, fear of fatness has been shown to decrease (Surgenor & Maguire, 2013). Further, starvation can distort how one expresses their levels of distress, meaning that clinicians may not be receiving accurate portrayals of how severely implicated one's psychological state has become by the disorder (Surgenor & Maguire, 2013).

Recognition can be made challenging and go unnoticed for a number of reasons including unintentional denial, comprised of the individual with AN having impaired self-awareness and reality distortions (Vandereycken & Van Humbeeck, 2008). There may also be deliberate denial about symptoms and minimization that anything is wrong, which may occur as an expression of avoidance and fear of the consequences (Gray, Murray, & Eddy, 2015; Vandereycken & Van Humbeeck, 2008). Some practitioners go as far as to say that those with AN do not wish to be diagnosed or have their AN be recognized, because they do not wish to be treated (Adlam, 2015; Cooper, 2005; Halmi, 2005).

In a national survey of physicians which aimed to explore the knowledge, skills, and needs around ED screening and intervention, 68% of physicians reported not assessing for EDs if the patient did not mention it as a concern (Linville, Brown, & O'Neil, 2012). Further, these

physicians reported feeling apprehensive about patient defensiveness and being unsure about what questions to ask. Since patients are unlikely to self-disclose their symptoms (Vandereycken, 2006), EDs are likely to go undetected in primary care settings. A more recent study examining ED detection in primary care found that 61% of physicians sampled were able to identify and diagnose an ED, however only believed that 40% of those individuals required a treatment referral (Higgins & Cahn, 2018), demonstrating not only concerns with recognition but also critical follow-up care.

Based on physicality alone, the prototypic individual with AN presents as malnourished and emaciated (Gray et al., 2015), yet just because there is a prototypic patient does not make the recognition of AN any easier as there can be multiple reasons for weight loss. Also adding to the ambiguous nature of recognition or assessment is that the behaviours and thoughts of someone with AN fall along the same spectrum of behaviours and thoughts that the majority of Western females have, that is a preoccupation with shape and weight (von Ranson & Wallace, 2014). In fact, awareness of the thin ideal is so widespread that Murnen, Smolak, Mills, & Good (2003) found that many children in Western cultures are aware of this sociocultural preference for a thin body by the first grade, or around the age of 6 years old.

Various practitioners including Brown and Jasper (1993), Neumark-Sztainer, Levine, Paxton, Smolak, Piran, and Wertheim (2006), Russell-Mayhew (2007), and Sundgot-Borgen and Torstveit, (2010) have argued for a continuum of weight and body preoccupation. Brown and Jasper (1993) proposed that it is not accurate to stigmatize AN as "individual pathologies or diseases, at the same time we approve, even praise, the behaviour of those women who exercise and diet to attain the culturally prescribed body ideal" (p. 54). Brown and Jasper (1993) offered that it is difficult to suggest that someone who meets the diagnostic criteria of AN is any more

pathological than someone who diets and engages in a rigid exercise routine for the purpose of controlling shape and weight. Feeling negatively towards one's body is a similar experience for women engaging in EDs and those dieting, as women internalize the ideal body image, recognizing that how they look will reflect how they are valued and treated (Brown & Jasper, 1993; Malson & Burns, 2009). A wide range of eating and weight related issues exist on a spectrum, ranging from negative body image and shape concerns to significantly distressing EDs such as AN and BN (Levine & Smolak, 2006; Neumark-Sztainer, 2005; Russell-Mayhew, 2007). In this vein then, the ambiguity presents itself when behaviours that are considered normal, even virtuous, go too far. Practitioners have suggested that there may be some commonalities in those with AN and those who diet to control weight (Brown, 1993; Cash, 2002; Neumark-Sztainer, Story, Hannan, Perry, & Irving, 2002), adding even more complexity to the assessment process.

Often, individuals with AN report a sense of self-confidence and feelings of worthiness after they have lost weight (Nordbø et al., 2006). In addition, individuals describe receiving positive feedback from others related to their shape and weight upon initially losing weight (Nordbø et al., 2006). Therefore, it is not surprising that these same individuals would experience tensions between the way they feel in their bodies after having lost weight and others conveying that they are concerned for them. Hence, the ambiguity must be endured by both the individuals with AN and the practitioners who are tasked with recognition. Apparently, not everyone in these situations share the same perspectives and at times might be in direct tension with the other (Vandereycken & Van Humbeeck, 2008). Finally, a qualitative study conducted by McCormack and McCann (2015) found that parents expressed guilt over not having identified the signs of AN earlier and wished they had sought help sooner. This overall lack of awareness was attributed to having little knowledge or information about the early symptoms of AN.

Evidently, there are multiple perspectives and positions in recognizing AN, emphasizing how this process in not black or white. Clear cut ways of recognizing that one is experiencing AN are not available.

Anorexia Nervosa Outcome Variability and Ambiguity

Treatment outcomes for AN are inconsistent, and of limited success for select individuals (Steinhausen, 2008). For instance, individuals remain at high risk for early relapse even after succeeding in weight restoration early in treatment (Carter et al., 2012; Khalsa et al., 2017). The limited success in treating AN is not the fault of individuals with AN, rather perhaps an issue of not having yet found a treatment that works well for all. According to the most exhaustive reviews of treatment outcomes of AN to date, among surviving patients 37% reached full recovery within four years after the disorder onset, 33% improved, and 20-25% developed a chronic course of AN (Berkman, Lohr, & Bulik, 2007; Steinhausen, 2002). The crude mortality rate is reportedly 5-9%, which is accounted for by suicide or medical complications from starvation or compensatory behaviours (Berkman et al., 2007; Steinhausen, 2002). Thus, according to our knowledge of the course of AN, particularly the course following treatment, reaching the recovery status is not cut and dry.

Anorexia Nervosa and the Role of Family

Much like how the conceptualization of AN has progressed throughout the past decade, so too has our understanding of etiological models of EDs. Not so long ago, family factors were believed to be primary mechanisms of ED psychopathology (Le Grange, Lock, Loeb, & Nicholls, 2010). In fact, some models of EDs blamed families, particularly parents, for causing their child's illness. In this section, I will outline the history of families perceived involvement and responsibility for the development and maintenance of EDs.

Although it is now appreciated that the etiology of EDs is multifaceted and complex (i.e., the biopsychosocial model), theories of family/parental causation are still in circulation. These family-based theories are overly simplistic and speculate that not only are family interaction patterns unique to EDs, but these family patterns are what cause and maintain the disordered features of the illness (Le Grange et al., 2010). Dating back to the 1970s, Minuchin and colleagues theorized that *anorectic families* could be characterized by rigidity, enmeshment, overprotectiveness, and poor conflict resolution (1978). The term *psychosomatic family* was coined to describe interactional family styles and patterns that was part of the etiology of EDs. Rigid families referred to those that did not allow for change to take place and were especially likely to experience difficulty during times of appropriate developmental transition. Enmeshed families were described as families where the boundaries between roles were unclear. Last, families with poor conflict management was an important aspect of Minuchin and colleague's psychosomatic family theory, referring to families where one parent was an avoider of conflict, regularly denying that a problem existed, detouring conflict or simply leaving the house during confrontation. These four general features (i.e., rigidity, enmeshment, overprotectiveness, poor conflict resolution) were believed to be the characteristics of psychosomatic families and created the environment for the ED symptoms to develop within the child. Further, Minuchin et al. (1978) theorized that psychosomatic families were hostile, intrusive, and not responsive to the individual with the ED emotional needs. Other research teams in the 1980s emphasized parental overprotection of children as a primary cause of EDs. In these theories, it was suggested that children were not able to develop autonomy or independence, leading to feelings of having no control over their own lives (Slade, 1982), which in turn, was a major factor contributing to the development of EDs. More generally, research on the dysfunction inherent within families

prevailed in academia throughout the 1990s, with publications on the dysfunctional family structures of youth with AN and BN prevalent in the literature (e.g., North, Gowers, & Byram, 1995).

While many researchers continued to study and theorize about the pathological family systems responsible for the development and maintenance of EDs, a paradigm shift began in the Maudsley Hospital in London, England in the late 1970s. Rather than presuming parental causation in the etiology of EDs, the focus shifted to including parents in the treatment of their children, appreciating them as a resource, while decreasing their feelings of guilt. Although the work being done at the Maudsley Hospital was progressive and an important historical turning point in the treatment of EDs, the field continued to examine the role of the family as a risk factor and causation for EDs. Many cross-sectional studies completed in the 1990s demonstrated that inappropriate parental styles and pressures uniquely defined ED patients from other psychiatric groups (Horesh et al., 1996), and that mothers of patients with AN were more overprotective and highly involved compared to mothers of control groups (Shoebridge & Gowers, 2000). Further, a community-based study found that there was more family change such as a parent leaving or a step-parent joining the family in the year prior to illness onset in a group of females with BN, compared to healthy controls (Welch, Doll, & Fairburn, 1997). These are samples from a wealth of literature on ED risk factors, and though they do not claim causation, certainly do suggest that family factors can be risk factors for psychopathology, that can later interact with other predispositions such as biologically rooted vulnerabilities (Klump, Bulik, Kaye, Treasure, & Tyson, 2009).

Though there is evidence against family-based theories of ED causation, these beliefs about parents causing EDs are still in circulation. While families can play a role in the genesis

and maintenance of EDs, current literature demonstrates family factors are not exclusively causing the illness (Le Grange et al., 2010). In 2010, prolific researchers and clinicians in the ED field published a position paper in the esteemed Academy for Eating Disorders journal. In this paper, Le Grange and colleagues (2010) made a clear stance refuting theories that suggested that families and parental styles were the main mechanisms that underlie risk for EDs, and concluded that efforts to alleviate the stress and burden of families should be prioritized over efforts to blame and accuse.

Family Caregiving, Functioning, and Anorexia Nervosa

Intervention guidelines for AN recommend the involvement of family members in the treatment of youth presenting with this disorder (National Institute for Health and Care Excellence, 2017). Given the recommended involvement of relatives, many researchers have studied the experience of caregivers. Literature suggests that parents are not prepared for the involvement or responsibility required in the treatment of their children, and often report difficulties across multiple domains of caregiving (Blondin et al., 2019).

Psychological distress, expressed emotion (i.e., a range of attitudes and behaviours that relatives express about the individual affected with AN), and caregiver burden have been identified as factors that family members caring for a relative with AN experience as difficult (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014; Blondin et al., 2019; Zabala et al., 2009). Caregivers for individuals with AN often report guilt, shame (Treasure et al., 2008), loss (Treasure et al., 2001), helplessness, self-blame, anxiety (Whitney et al., 2005), decreased self-worth (Kyriacou et al., 2008), and an overall reduced quality of life (de la Rie, Van Furth, De Koning, Noordenbos, & Donker, 2005). Further, caregivers report feeling blamed for their loved one's illness (Honey et al., 2008). In fact, caregivers for those with AN report similar levels of

burden to those caring for relatives with psychosis (Treasure et al., 2001; Zabala et al. 2009), highlighting the tremendous social impact that AN has on caregivers and family members. Quantitative studies have demonstrated higher degrees of burden to be found among families caring for individuals with longer illness durations (moderate illness durations 3-7 years and extreme illness duration- more than 7 years) compared to families with relatives experiencing EDs for shorter durations (0-3 years; Anastasiadou, Medina-Pradas et al., 2014). Hence the length of time a family member is ill negatively impacts caregivers' mental states and prolongs tensions within the family. Further, among the negative aspects of caregiving for a child or adolescent with AN, parents report that the sense of loss contributes most to emotional over involvement, while the youth's difficult behaviours contribute most to parent's critical comments (Blondin et al., 2019). Emotional over involvement refers to an individual's attitudes of sacrifice, over worrying, and instances of intense emotions. Critical comments are defined as direct criticism or indications of dissatisfaction. It seems as though parents' perceptions of their child and their future trajectory are strongly dependent on their tendency to be overly involved. Blondin and colleagues (2019) proposed that the perception of disruptive behaviours in the child/adolescent with AN may be one factor that exacerbates parents' critical comments and attitudes. Not surprising, compared to family members of healthy individuals, a systematic review of families caring for individuals with EDs suggested anxiety, depression, and stress scores were consistently greater for this group (Goddard & Treasure, 2013).

A recent meta-ethnography, analyzing 16 peer-reviewed articles about caregivers found three core experiences that captured the essence of caring for someone with an ED: external factors, reactions, and output behaviours (Quong & Chen, 2018). Externally, caregivers (mostly parents) reported that perceived barriers, managing the healthcare system, and perceived

supports influenced their cognitions and behaviours while caring for someone with an ED. Perceived barriers included: stigma, time and finances, loss of normalcy and routine, and lack of information obtained throughout the detection and treatment process. Particularly relevant to this current study is the finding that parents were often confused and felt left behind in terms of feeling knowledgeable about the assessment and treatment of their child with an ED (Cottee-Lane, Pistrang, & Bryant-Waugh, 2004; Highet, Thompson, & King, 2005). In fact, many parents reported receiving conflicting advice and information from various health care professionals, inevitably leading them to question themselves and not know how or where to access resources (Cottee-Lane et al., 2004). Further, many parents felt devalued and misunderstood when given partial information or were not consulted for critical decisions in their child's care (Honey et al., 2008; Keitel, Parisi, Whitney, & Stack, 2010). The second core theme Quong and Chen (2018) suggested was caregiver reactions, meaning the psychological, social, and physical reactions based on the abovementioned external factors. Aside from exhaustion, worry, uncertainty, and feelings of powerlessness, caregivers reported difficulties caring for themselves. In fact, caregivers reported feeling like taking time for themselves was selfish, as that was time taken away from the individual with the ED (Patel, Shafer, Brown, Bulik, & Zucker, 2014). In line with difficulties with self-care, caregivers reported trouble with sleeping and eating and increased illness (Dimitropoulos, Klopfer, Lazar, & Schacter, 2009). Finally, the third core theme suggested by Quong and Chen (2018) was output behaviours, including the development of acceptance and the process of coping. Four stages were identified in the development of acceptance: (1) normalization; (2) denial; (3) suspicion, search, and reassurance; and (4) recognition and acknowledgement. Concurrently, caregivers also went through six phases of coping, including (1) maladaptive strategies, (2) help seeking, (3) learning skills, (4)

cognitive strategies, (5) taking control, and (6) personal growth and hope (Quong & Chen, 2018). Though many caregivers transitioned through these behavioural continuums, Quong and Chen (2018) concluded that not every caregiver reaches acceptance or develops adaptive coping behaviours. Thus, caregivers of individuals with EDs live through a dynamic time, facing barriers, managing the healthcare system, learning about the disorder, adjusting family dynamics and expectations, and developing acceptance and coping attitudes and behaviours.

Not only can the presence of a family member experiencing AN cause increased levels of anxiety, depression, stress, and burden, but family dynamics and functioning of parents can also change. Many families with children with EDs in general, report that the child with the ED becomes the central focus, causing families to reorganize around them (Whitney & Eisler, 2005). A qualitative study exploring the perspectives of adolescent females diagnosed with AN demonstrated that the presence of AN can mean that parents divide their time and attention between their children affected and not affected by AN (Honey, Clarke, Halse, Kohn, & Madden, 2006). While parents were caring for the welfare of the child with AN, they also reported having to make difficult decisions in the parenting of their unaffected children. Decisions influencing family functioning included: maintaining or disrupting normal family routines, providing emotional support, and protecting and monitoring siblings (Honey et al., 2006). Further, many parents already experiencing distress and anxiety about their child with AN reported experiencing additional distress when seeing the negative impact of the AN on their other children and the relationships between the siblings. In one case, Honey et al. demonstrated this tension with the following quotation:

> [My husband] felt that it would be probably not beneficial to [my son] if he sort of jumped on the, you know, let's get our daughter better bandwagon and, and left him to

> his own devices. So he said no, look, you deal with Paula… I'll be the rock for James. (2006, p. 319)

Clearly, the experience of having a child with AN has the potential to change the family dynamic and force parents into splintered roles. Parents face difficult decisions in how their family continues to structure and function, decisions which may affect the perceptions of the individual with AN, their experience of AN, and their recovery. Though this literature is not specific to the exact moment of discovering one's child is experiencing AN, it does paint a picture of the different responses families have once the AN has been recognized.

Differences between mothers and fathers. Parents may be required to take different positions and roles within the family when caring for a child with AN. When gender differences are taken into account, Goddard and Treasure (2013) found slightly higher levels of depression for mothers whereas higher levels of stress were observed in fathers of children with EDs. When time spent towards caregiving was assessed in a sample of parents whose children were receiving outpatient treatment for AN, mothers reported spending 2 – 5 times as long as fathers with caring tasks (i.e., medical, food, practical related care and emotional support; Rhind et al. 2016). Mothers in the study reported a median of 2.5 hours a day, compared to fathers who reported a median of 1 hour a day. Based on self-reports, mothers spent significantly more time caregiving, except in the area of practical care. Interestingly, a different research team suggested that their within-study findings indicated that mothers struggled due to being overly involved emotionally with their child, whereas the fathers tended to be more critical of their child's experience (Anastasiadou, Cuellar-Flores, Sepulveda, & Graell, 2014; Kyriacou et al., 2008; Whitney et al., 2012). This finding is not surprising given that mothers generally are responsible for caring for their children and spend greater amounts of time doing so, therefore experiencing greater levels

of anxiety and negative emotion. These heightened emotions thus turn into over involvement with the course of their child's illness and in the recovery process. Conversely, Anastasiadou, Cuellar-Flores and colleagues (2014) suggested that, due to their lesser degrees of involvement compared to mothers, fathers of children with EDs typically display higher levels of criticality, which tend to be associated with misperceptions and lack of understanding of EDs.

In contrast to the differences found between mothers and fathers in Anastasiadou and colleagues (2014) study, Blondin et al. (2019) determined that different dimensions of expressed emotion between mothers and fathers were observed after a child's first hospital admission for AN. Of the 50 mothers who participated, the eight negative aspects of the caregiving experience (i.e., difficult behaviours, negative symptoms, stigma, problems with services, effects on family, sense of loss, dependency, need to backup) were significantly and positively associated with emotional over involvement. Whereas, these patterns of association were not the same for the 38 participating fathers. Although father's emotional over involvement scores were significantly and positively related with problems with professional services, stigma, and sense of loss, scores indicated that fathers were more emotionally over involved when they perceived their child had increased needs. In contrast with mothers, the fathers' ratings of emotional over involvement were not linked to disruptive behaviours, like it was for mothers. Further, all negative dimensions of caregiving for mothers were significantly and positively correlated with their expression of critical comments, whereas for fathers, only difficult behaviours, negative symptoms, effects on the family, and sense of loss were significantly and positively associated with critical comments. Thus, Blondin and colleagues (2019) suggested that only disruptive behaviours are associated with critical manifestations for fathers. Consequently, within families, family members respond distinctly to a child affected by an ED, and may also respond starkly

different when faced with the discovery. The consequences of family member's responses to discovery are unknown and may be illuminated by the current research.

Family Influences on the Maintenance of Anorexia Nervosa

Families' high levels of burden, psychological distress, and dysfunctional responses have been demonstrated as maintaining factors for AN (Anastasiadou, Medina-Pradas et al., 2014). Specifically, the ways in which family members express themselves and/or accommodate to the symptoms can impact the outcome for the individual experiencing AN and possibly exacerbate the symptoms (Treasure & Schmidt, 2013). This cycle of family dynamics and exacerbation of symptoms has been proposed as an interpersonal maintenance model of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). Emotional responses to the AN symptoms may inadvertently play a role in the maintenance of the problem, and families can become stuck in these unhelpful patterns of interaction and accommodation (Treasure et al., 2008). Behaviours of accommodation are actions that allow or enable AN symptoms to continue and might include: giving into rules about food preparation and eating rituals, allowing aberrant behaviour at home, and modifying family, work, or social schedules to accommodate for the abnormal eating behaviours (Sepulveda, Kyriacou, & Treasure, 2009). Sepulveda and colleagues (2009) concluded that maintenance and accommodation behaviours appeared to be more present when (a) the duration of illness was longer, (b) the individual with AN and family caregiver spent more time together, and (c) the affected individual experienced AN rather than BN. In a study conducted with parents of children receiving outpatient treatment for AN, the Accommodation and Enabling Scale for EDs (Sepulveda et al., 2009), assessing avoidance and modifying routine, reassurance seeking, meal ritual, control of family, and turning a blind eye, found the level of accommodating behaviours of fathers was lower than that of mothers (Rhind et al., 2016). Rhind

and colleagues (2016) suggest that accommodations are meant to reduce the distress and anger of the individual with AN. This literature demonstrates the difficulties and nuances of caring for an individual with AN, and the accommodating behaviours that caregivers may enact to lessen the burden of caring in some way.

Responses to Anorexia Nervosa Predicting Recovery Outcome and Help Seeking

Understanding the experiences of parents who have discovered they have a child living with AN is important because it could help us better understand the association between the response to discovery and help seeking. Family members and friends are cited as the most likely recipients of ED disclosure (Becker et al., 2005). Although disclosing to a friend did not predict help seeking, when someone else initiated the disclosure by asking questions or making comments about the symptoms and acted positively, help seeking was sought faster (Gilbert et al., 2012). This association may be translated into the responses from family members after discovery. The way in which one responds to the discovery that their child has been experiencing AN is significant since positive and supportive responses are associated with faster help seeking (Gilbert et al., 2012), and because time is of the essence in the treatment of AN (Treasure & Russell, 2011). The longer the duration of untreated illness, the worse the prognosis becomes (Treasure & Russell, 2011). Further, the response to treatment is greatest in the initial stages of the illness (Treasure, Stein, & Maguire, 2015). Evidently the role that others play as the recipients of discovery and how these recipients manage their responses is instrumental in the next steps an individual chooses to take regarding AN.

Putting the Pieces Together: Mothers' Experiences of Discovery

Aside from academic literature, several parents of children with AN have shared their experiences of discovery in online news platforms. These informal accounts are compelling in

that they demonstrate the variability of this experience, illustrating the different ways in which families discover, their reaction to the discovery, how long the illness had been already present, and factors making each individual with AN unique. Discovering one's child has AN and has been living under the same roof of their unknowing parents causes extreme distress, as these mothers' report.

A mother from the United Kingdom shared her experience in the Telegraph, describing that before her daughter became ill, she believed that individuals with EDs simply wanted attention, were bored, and self-destructive (Brown, 2011). After explaining her biases, Brown painted a picture of a healthy, active daughter, who slowly began to become thinner even as she grew taller. Brown recalled her daughter crying continuously and being more preoccupied with things that would not cause others to worry in the months leading up to the eventual discovery. In a powerful excerpt, Brown offered,

> Most parents of an anorexic child can look back on a day when they should have done something but didn't. A day when they first realized something was very wrong but still had no words for it, just a feeling. (Brown, 2011, para. 6)

Brown continued to offer how the process of discovery unfolded over time, slowly learning and realizing the full extent of what was happening to her daughter. Brown recounted various examples of recognizing signs of AN (e.g., goose bumps on her daughter's arms on a hot day, developing an obsession for cooking yet not eating the final product, meal time rituals). Since she observed these things gradually over an extended period, she only acted on her concerns by scheduling an appointment with a pediatrician well into her daughter's illness. Brown described becoming more observant of her daughter's changing behaviours, moods, and body. In

hindsight, Brown made mention of wishing that she had paid even more attention, wishing that she had somehow acted on the feeling that something was not right.

Another account from a mother from the United Kingdom published in Mail Online, recalled receiving a phone call from concerned teachers at her daughter's school (Walker, 2013). To Walker's horror, teachers conveyed their concerns that her daughter was no longer eating lunch and had lost a considerable amount of weight. Walker recalled the disbelief she felt upon the discovery, "I slumped in a chair, literally reeling with shock and guilt as my mind started a frantic scramble for clues" (Walker, 2013, para. 5). Walker's story is unique compared to other parent narratives in that she was a clinical psychologist, specializing in the treatment of EDs, making this discovery even more surprising. She shared, "my guilt was compounded because, of all people, I should have been able to see what was going on" (Walker, 2013, para. 9). Clearly, even those with professional training in the area of EDs are caught by the surprise that their child was experiencing AN, apparently not observing the signs or symptoms they are trained to look for in the clients they treat professionally.

Summary

Evidently, the variations of discovering one's child has been experiencing AN are endless, and parents' responses to these discoveries are also infinite. Though these accounts were not produced within the academy, they do illustrate this complex phenomenon and help others to understand the chaos not only inherent within the person with AN's life, but also the family too. When entering into a topic that is unknown, a topic that can take on many directions, possibly with countless leads to follow, a method that is adaptable, welcomes uncertainty, and open to possibility is necessary. In the following chapter, I introduce hermeneutic inquiry as a

philosophy and method combination, and how it will be used to help me explore how parents discover that their child is experiencing AN.

Chapter Three: Hermeneutic Inquiry: Method of Interpretation

> Interpretation is not an occasional, post facto supplement to understanding; rather, understanding is always interpretation, and hence interpretation is the explicit form of understanding. (Gadamer, 1960/2013, p. 318)

Hermeneutic inquiry, most simply put, is a way of interpreting the world. *Interpretation* refers to when an unfamiliar meaning is made understandable (Grondin, 1994). Hermeneutic inquiry is an approach to exploring and understanding a topic based on philosophic hermeneutic principles of understanding, dating back to the 17th century (Grondin, 1994). The word hermeneutic comes from the Latinized form of the Greek word *hermeneutikos* meaning "of or for interpreting," from *hermeneutes* meaning "interpreter," and from *hermeneuein* meaning "to interpret (foreign languages); interpret into words, give utterance to" (Online Etymology Dictionary, n.d.). Evidently, when undertaking hermeneutic inquiry, the task for the researcher is to find how they might better understand their topic of interest, through interpretation. In this chapter, I offer the history, evolution, and eventual conception of hermeneutic inquiry, describe it as both a philosophy and method, and provide a discussion of the utility of this method in applied practice disciplines, such as counselling psychology. I conclude with a description of the process of participant recruitment, data collection, and relevant ethical considerations for this research.

Hermeneutic Landscape: Looking Back in Time

The classical discipline of hermeneutics was concerned with the art of understanding theological texts (Gadamer, 1960/2013). The discipline later evolved to study texts more generally, then shifted once more to focus on the humanities (Moules, McCaffrey, Field, & Laing, 2015). Eventually, Hans-Georg Gadamer's philosophical hermeneutics was applied to

practice, which is the branch of hermeneutics employed for the research. Before Gadamer revolutionized the study of interpretation, key figures throughout the 19th and 20th century were greatly influential.

Schleiermacher (1768-1834)

Schleiermacher was a professor, theologian, and a translator of Plato (Grondin, 1994). During his time, hermeneutics was parted into specialized ways of understanding theology and law, with specific techniques for each discipline. Schleiermacher sought to establish a more universal basis for hermeneutics which could be applied across disciplines (Moules et al., 2015). Schleiermacher recognized the critical role of language in one's ability to understand, hence he identified language as integral to hermeneutics. Schleiermacher understood there to be a dialogic relationship between two elements of language: the expression or utterance of thought by one person and its comprehension by another (Grondin, 1994). This theme of the dialogical relationship, is an integral element from which future hermeneutics was built upon (Moules et al., 2015).

Schleiermacher claimed there to be different kinds of interpretation and differentiated between grammatical and psychological/technical interpretation (Grondin, 1994). Schleiermacher's grammatical interpretation acknowledged that meanings of words not only consisted of their dictionary definitions, but also the context in which the word was used (Grondin, 1994). Psychological interpretation, or technical interpretation as Schleiermacher originally referred to it, conversely referred to reconstructing what the author of an original text had thought or intended in his writings.

Finally, worth noting in regard to his contributions to hermeneutics, was Schleiermacher's stance of misunderstanding. He believed "hermeneutics becomes necessary

only when someone does not understand (any longer)… From the outset, then, the interpreter must be on guard against possible misunderstanding" (Grondin, 1994, p. 70). Therefore, according to Schleiermacher, understanding is something to be attained and hermeneutics became a way of understanding available to all humanistic disciplines (Palmer, 2007).

Dilthey (1833-1911)

Schleiermacher's approach to applying hermeneutics as a way of understanding for all disciplines was taken up by Dilthey who wanted to position hermeneutics as a fundamental methodology for all of the humanities (Palmer, 2007). Dilthey was a philosopher and historian (Grondin, 1994). Dilthey tasked himself with conceptualizing the human sciences as autonomous sciences and used his work to defend them from the infringements of the natural sciences and their methods (Grondin, 1994). Dilthey sought to provide legitimization to the human sciences and used the concept of historicism to do so. Historicism refers to the idea that a topic must be understood in relation to its time, as values, beliefs, and cultures evolve with the era they exist in (Moules et al., 2015).

In his efforts to use hermeneutics as a method for all humanities, Dilthey made the claim that the distinction between human and natural sciences had to do with the inner experiences of the subjects being studied in the human sciences (Moules et al., 2015). Dilthey claimed that human sciences were about understanding a phenomenon, rather than explaining or describing it, therefore the human sciences contained both subjective and objective values. Dilthey coined the term *lived experience* and used it to describe the creation of meaning across time by making connections between unrelated events (Moules et al., 2015). Further, Dilthey used the term *expression* to describe the outward manifestations of experience. In this regard, Dilthey asserted that the human sciences had objective parts to study, since expressions were concrete, outward

demonstrations of subjective inner experiences (Moules et al., 2015). Dilthey sought to establish universal rules to make hermeneutics a rigorous, structured methodology, however such rules were never explained (Grondin, 1994).

Husserl (1859-1938)

Much like Dilthey, Husserl formulated a response against the increasingly insistent claims that the natural sciences were superior and more trustworthy than the human sciences (Gadamer, 1960/2013). In his work, Husserl rallied for careful attention to detail when studying human experience, in which he argued provided a rigorous analytic procedure and way to study the human sciences (Moules et al., 2015).

Husserl was interested in careful description and analytic inquiry of human phenomena, in which he referred to as *phenomenological reduction*. Important to Husserl's contributions to hermeneutics was his emphasis on intentionality. Intentionality described how humans are committed to and conscious of the world and their experiences. By this, Husserl meant seeing something as something, always being conscious of something (Moules & McCaffrey, 2017). Husserl used this notion of intentionality to argue that to study human experiences, a phenomenological method must be applied to our understanding about the concreteness of the world (Moules et al., 2015).

Phenomenology. The phenomenological method that Husserl introduced required a process of reduction – ridding the phenomenon of all its context, thus leading to the phenomenon's essence. By reducing the topic to its simplest form, Husserl declared that this method could lead to understanding the true nature of things, or something in its purest form (Moules et al., 2015). *Reduction* was the term Husserl used to describe how one consciously sets aside all extraneous factors to arrive at the essence of the phenomenon (Gadamer, 1960/2013).

Further, the idea of *bracketing*, or the act of suspending judgement when studying a subject was developed in the same vein (Gadamer, 1960/2013). Both are concepts taken up in the phenomenology research approach, which is different than but related to hermeneutics.

Phenomenology and hermeneutics. While tracing the influential figures of philosophical hermeneutics, it is helpful to note the similarity and distinction between phenomenology, an approach that Husserl is credited with, and hermeneutic inquiry. Phenomenology, as stated above is the study of human experience that attempts to provide the complete description and purity of the phenomenon. Phenomenology claims that there is no interpretation in pure description, as getting down to the essence of something requires suspending one's pre-conceived notions, biases, and judgments about the topic of inquiry (Moules et al., 2015). Conversely, hermeneutics relies on these judgements and prejudices to understand the topic (Gadamer, 1960/2013).

Heidegger (1889-1976)

Heidegger was a student of Husserl's, and took phenomenology in a profoundly different direction. Removing the bracketing that was integral to Husserl's phenomenology, Heidegger believed that humans are already living in the situation under study, so it is not possible to rid ourselves of factors that might influence our understanding of a topic (Grondin, 1994). Central to Heidegger's work was the concept of *Dasein*, meaning to be in the world, or the fundamental mode of being which is distinctive for human beings (Brandom, 1983; Grondin, 1994). Heidegger made clear that his use of Dasein was intended to characterize humans' capacity for self-reflection and understanding of the situation they are situated in (Moules et al., 2015). In this regard, according to Heidegger, we are already involved with life, making it neither purely objective or subjective (Moules et al., 2015). Humans are implicated in the movement

happening in the world and are oriented by their relationships to others and the world. Rather than describing a phenomenon stripped from its context, Heidegger was focused on paying close attention and to using language carefully in order to describe the nuanced, complex, and relational character of life as it exists (Moules et al., 2015). This last emphasis remains an integral part of hermeneutic inquiry.

One major difference between Heidegger and his teacher Husserl was the way in which they saw the fixity of the world. Husserl believed the world had stagnant properties and essences, whereas Heidegger saw the world and events happening in it as interrelated and layered (Moules et al., 2015). In Heidegger's view, the wold is constantly revealed to us through our engagement with it.

> It is not the case that first there are naked things "out there" which are subsequently given a certain coloring by our "subjective" and circumspective understanding. On the contrary, what is primarily there is precisely our involvement in the world, which takes the form of interpretive project. (Grondin, 1994, p. 95)

Further, Heidegger asserted that it is necessary to make one's own situation transparent, so that the otherness from the text or topic trying to be understood may be noticed (Grondin, 1994).

Gadamer (1900-2002)

Gadamer is considered one of the most important philosophical voices of the 20th century (Gadamer, 1960/2013). He was a student of both Husserl and Heidegger, and took up the linguistic and ontological themes from his teachers' work in his ongoing philosophizing about how we come to understand. In his major written work titled *Truth and Method* (1960/2013), Gadamer presented his understanding of the world to be ever changing, rooted in history and language. Thus, since Gadamer attested that understanding is expected to change, his

hermeneutics, known as philosophical hermeneutics, (Grondin, 1994) readily applies to practice disciplines.

Hermeneutics as a Philosophy and Method

Hermeneutic inquiry has been described as a "practice and theory of interpretation" (Moules et al., 2015, p. 3), applied when understanding experiences and phenomena occurring within the world. When using hermeneutic inquiry to better understand a topic, researchers do not apply principles or rules of systematic understanding to instances, because as Caputo (2015) described, this would suggest that the topic and instances within it being examined are pre-determined. Consequently, philosophical traditions refined over the last 2000 years guide the research and practice of hermeneutic inquiry.

Universality and Finitude

Gadamer's ideas guiding his philosophical hermeneutics assume universality, based on the fact that all human behaviour is rooted in making sense of things, even if unconsciously (Grondin, 1994). Since the world and worldly phenomena are interpretable, this means that we live in a world that is and can be understood through language. "The ability to understand, then, is a fundamental endowment of man, one that sustains his communal life with others and that, above all, takes place by way of language and partnership of conversation" (Palmer, 2007, p. 158). Thus, hermeneutics is universal.

Along the same vein, Gadamer claimed that our understanding of the world is finite, thus we are never capable of producing a complete interpretation or understanding of a phenomenon (Gadamer, 1960/2013). This finitude is one of the main principles of hermeneutic work according to Moules and colleagues (2015), as they asserted that researchers have to start their

inquiry somewhere and also finish it somewhere, while the life and trajectory of the topic continue.

Historically Effected Consciousness

> We always find ourselves within a situation, and throwing light on it is a task that is never entirely finished… The illumination of this situation – reflection on effective history – can never be completely achieved; yet the fact that it cannot be completed is due not to a deficiency in reflection but to the essence of the historical being that we are. *To be historically means that knowledge of oneself can never be complete.* (Gadamer, 1960/2013, pp. 312-313, italics in original)

Gadamer's philosophical hermeneutics makes claim that, to understand a topic, one must recognize the temporal dimension associated within it. According to Moules and colleagues (2015), strong, cogent interpretive work attends to the history of the topic. While recognizing that interpretation has a temporal element, hermeneutics intriguingly makes clear that the topic is already happening, collecting more of a history as each day passes. In order to understand, one must enter into that conversation with parts of the interpretation already in the past. Further to this point, Gadamer made clear that we are always in the flux of history. "We can consciously do our best to clarify our understanding from within the flux, but what we cannot do is step out of history" (Moules et al., 2015, p. 38). Hermeneutic inquiry therefore calls for researchers to be aware and responsible for understanding the topic and its history.

Historically effected consciousness also relates to the hermeneutic notion that one can never truly capture all of the possibilities about a topic, because the world is constantly changing and so too is the individual interpreting it. Gadamer used the word *tradition* in his writing about the importance of history in our understanding of a topic. He used this term to convey that

researchers cannot and must not assume that they can study a topic as blank slates, but rather we must approach a topic with its history and traditions in mind, in order to best understand.

Grondin (1994) noted, "history is at work where we imagine ourselves superior to it" (p. 114). By this, he meant that, as individuals try to interpret the world, history impacts the horizon of understanding, making it impossible for ultimate clarification of the topic. Further, the concept of historically effected consciousness has more than one meaning. On one hand, the term refers to our consciousness being effected and constituted by history, while conversely, the term also suggests that since history is always in effect, the task of understanding ourselves will always have to be undertaken (Grondin, 1994).

Fusion of Horizons

Fusion of horizons is the English translation of the German word *Horizontverschmelzung,* frequently occurring throughout Gadamer's *Truth and Method*. The term refers to the coming together of understandings to achieve new or transformed considerations of the topic (Moules et al., 2015). Gadamer (1960/2013) noted that the concept of horizon is essential to hermeneutics, as it refers to the range of vision that can be viewed from a particular vantage point. Thus, an individual with no horizon is not able to see far enough ahead, and over-values what is closest to him, evidently impacting his understanding of the situation. In addition, Gadamer explained that "to acquire a horizon means that one learns to look beyond what is close at hand – not in order to look away from it but to see it better, within a larger whole and in truer proportion" (1960/2013, p. 316).

A fusion of horizons in the hermeneutic sense refers to (a) the fusion of history and the notion of the coming together of the present, past, and future; (b) the fusion of horizons that occurs when researchers read texts from the past, therefore fusing their current understanding to

the history and tradition of the topic; and (c) the fusion occurring when two people engage in conversation and both come away with a new understanding of the topic, resulting from a sincere intent to listen to the others' point of view. In this last sense of fusion of horizons, the conversation partners do not have to agree about the topic, but rather they recognize that a new understanding is possible (G. McCaffrey, personal communication, June 2, 2017). Of note, a horizon is something one cannot see over or beyond. There is always a limit to how far one can see, relating directly to Gadamer's argument that hermeneutics is universal and finite.

Language

Gadamer emphasized the role of language in one's ability to interpret. He noted that a distinctive feature of language is that it can give expression to everything (Grondin, 1994). Language in hermeneutics does not necessarily mean solely linguistic communication, but can also include body language and inner dialogue. Inner dialogue refers to the content of individuals' thoughts. What is significant about inner dialogue is the idea that individuals "always mean more than is actually expressed" (Grondin, 1994, p. 123). Regardless of the form of language, Gadamer asserted that it is the universal medium in which understanding occurs, and especially in which the hermeneutic experience unfolds (Gadamer, 1960/2013). Language has a referential function, allowing humans to create things, to connect with others, to tell narratives about their lives, and importantly to connect to the past, present, and future (Field, 2017).

Conversation

Related to the philosophical hermeneutic pillar of language, conversation may be Gadamer's most distinctive idea about language (Moules et al., 2015). Gadamer wrote about conversation as occurring as a social form of open dialogue, allowing new understanding to arise

as individuals talk and listen to the other's contribution or point of view (Gadamer, 1960/2013). Central to Gadamer's hermeneutics is the notion of a genuine conversation, where both parties are open to the conversation and find themselves subordinated by the flow of the conversation itself, thereby allowing the topic matter to lead. According to Gadamer, in a genuine conversation, each party opens themselves up to the other and accepts the others' point of view as valid, thus a conversation is the process of coming to an understanding (Gadamer, 1960/2013). Further it should be noted that, while in conversation with another, each party is "speaking out of traditions that precede them, using words that are already saturated in cultural meanings" (Moules et al., 2015, p. 41). In this way, language has us; we do not have language (Heidegger, 1971).

Questions

In hermeneutic inquiry, researchers learn and might better understand the topic by asking questions. Researchers influenced by philosophical principles of hermeneutics ask questions that they do not know the answer to, rather than for superficial intentions. In this way, questions posed in hermeneutic inquiry come from a place of humility and genuine curiosity (Moules et al., 2015). Hermeneutic questioning is based on an inquisitiveness and an openness to what the other might say, while being open to the possibility that one may be surprised from learning the response to their question. Every statement has to be viewed as an answer to a question that could have been answered differently (Moules et al., 2015). The only way to understand a statement is to find the question to which its statement is an answer (Palmer, 2007). Accordingly, the goal of questioning is to understand the topic better.

Play

Gadamer introduced the notion of play as a way of being fully involved in the interpretation of the topic, to be caught up in the back and forth and flow of possible meanings. To be at play means one is engaged in the topic, absorbing it, and is responsive to the game (or the evolution of the topic). "In being presented in play, what is emerges. It produces and brings to light what is otherwise constantly hidden and withdrawn" (Gadamer, 1960/2013, p. 117). Further, Gadamer (1960/2013) pointed out that while playing, we are able to be at a place in between, which emphasizes play as a process. Play is an example of the movement that interpretation can take on when one is caught up in the possible meanings of the topic and are witness and involved in the cross currents of the topic's presence and place in the world (Moules et al., 2015).

Prejudice

Prejudice, according to Gadamer, refers to the idea that everyone comes to a topic with some background knowledge or already acquired belief or value. For him, prejudice was a part of the structure of understanding (i.e., the existing horizon against which we see, the attachments to the world that enable us to think something about something else in the first place; G. McCaffrey, personal communication, June 8, 2017). As Moules and colleagues (2015) articulated, "understanding is always about something that is already there, which means we can never start as if with a blank slate" (p. 43). Given that prejudices are inescapable, it is critical that researchers applying philosophical hermeneutics to their work be reflexive about their preconceived biases or concerns for a topic and remain open to other possibilities.

Gadamer considered prejudices or fore-understandings to be "conditions of understanding" (Grondin, 1994, p. 111). In fact, individuals are led by their historicity and strive for understanding because they are led by their expectations (Grondin, 1994). Further, it is not

possible to set aside one's prejudices and become an objective observer of phenomena, but rather the task in hermeneutic inquiry is to identify them and work them out interpretively (Grondin, 1994).

Hermeneutic Circle

The hermeneutic circle refers to relating parts of the world, to the whole of the world in our understanding of it. Further, this hermeneutic concept refers to the circular relation between interpretation and understanding (Grondin, 1994). Gadamer asserted that the interpreter is changed in the process of understanding (Moules et al., 2015). To elaborate, one may visualize a spiral design while considering how the whole of the research topic continues to be influenced by the partial understandings or accounts of the experience. Gadamer noted,

> A person who is trying to understand a text is always projecting. He projects a meaning for the text as a whole as soon as some initial meaning emerges in the text… Working out this fore-projection, which is constantly revised in terms of what emerges as he penetrates into the meaning, is understanding what is there… This constant process of new projection constitutes the movement of understanding and interpretation. (1960/2013, pp. 279-280)

As the researcher listens and engages with more participants, their interpretation of the topic continues to evolve, with each account adding more to the whole of the topic.

To understand a topic hermeneutically requires one to be prepared for the topic to tell them something that was not expected (Gadamer, 1960/2013). The hermeneutic circle is essential for all understanding, "it is neither subjective nor objective, but describes understanding as the interplay of the movement of tradition and the movement of the interpreter" (Gadamer, 1960/2013, p. 305).

Phronesis

Phronesis, meaning practical wisdom, is a term that Gadamer took from Aristotle (Moules et al., 2015). Phronesis refers to the application of knowledge and skill in unique and specialized areas, thus representing why hermeneutic inquiry is taken up by researchers in practice disciplines. Since Gadamer was committed to uncovering and interpreting pragmatic, factual life, he based his understanding in the practical sense (Moules et al., 2015). Gadamer looked to acquire understanding "of how to act well in concrete, particular circumstances" (Moules et al., 2015, p. 77), thus why this Greek term appears throughout his writings.

Aletheia

Fundamental to the practice of hermeneutics is the concept of *aletheia*, describing a process of uncovering pieces of understanding, at the expense of closing others (Moules, 2002). The specifics of a topic are both hidden from us and visible at the same time. The Greek term aletheia has several meanings. The first means to open, or to find a portal of understanding. In terms of the topic, researchers must look for questions that will open their understanding or opportunity to learn about the topic in its complexity. Second, aletheia contains the word *lethe*, referring to the mythical river of Hades that was said to cause forgetfulness of the past when drunk (or crossed) from (Online Etymology Dictionary, n.d.; Moules et al., 2015). Thus, in hermeneutic inquiry one must remember what has been forgotten. This points to the relationship between remembering and forgetting for any given topic. Finally, aletheia is about bringing to life what was taken for granted, or what was assumed about the topic (Moules et al., 2015). Evidently, aletheia captures an ambivalence about what we have to sacrifice in order to appreciate something else.

In summary, Gadamer philosophized and wrote at length about the philosophical concepts previously outlined. These are the pillars of Gadamer's philosophy for understanding and living in a world that continues to change, a world that is interpretable.

Applied Hermeneutics

In hermeneutic inquiry, attention is placed towards instances of the particular rather than instances that repeat and are seen most frequently (Gadamer, 1960/2013; Moules et al., 2015). Hermeneutics calls forth the routine and pieces of life that are taken for granted, and makes them salient and stand out. When standing out though, the topic does not stand alone but rather it stands with history, tradition, and relationships (Moules, 2002). Finely put, "hermeneutics takes the risk of embracing the coming of what we cannot see coming" (Caputo, 2015, p. xiii).

Hermeneutics: Finding Fit on the Fringes for the Current Research

Hermeneutics, as an applied method, is difficult to put one's finger on. The practice of applying the philosophical pillars of hermeneutics to guide research is challenging to categorize. For hermeneutic inquiry, this ambiguity and openness to possibilities is not considered a problem or a down fall of the approach to understanding, but rather this resistance to categorization is an asset (Moules et al., 2015). In the same sense that hermeneutics is difficult to categorize, the topic that I am interested in better understanding, parents' experiences of learning their child has AN, is somewhere in the middle of different fields. The topic finds its place, or lack thereof, on the fringes of counselling psychology, clinical psychology, and health psychology. Further, the topic is not quite situated in disease prevention, health promotion, education, or stigma management. This location on the fringes of different specialities parallels hermeneutics place as being associated with philosophy and method, thus presenting the first reason why this approach to understanding was selected.

In addition, hermeneutics requires a tolerance of uncertainty, both of the topic and interpretation (Moules et al., 2015). Researchers are constantly stumbling and pushing through their interpretations, never quite grasping the whole of the topic, and not ever capable of un-concealing the total tradition of the topic. When reading texts or interview transcripts, to read hermeneutically means that one must read against the text, not looking for the literal meaning of the others' words but rather to search for the intentions of the other. To look for possible meanings and understandings of the topic requires one to oscillate within a world of uncertainty and mystery. As Gadamer noted, "the true locus of hermeneutics is this in-between" (1960/2013, p. 306). This acceptance of ambiguity is also required of professionals working with and families living with individuals experiencing AN (Williams et al., 2018). The uncertainty and inconsistency of AN treatment (Hubert Lacy & Sly, 2015; Steinhausen, 2008), the mystery that is recovery (Berkman, Lohr, & Bulik, 2007; Steinhausen, 2002), and the secrecy and concealment typical in patients treated for AN (Basile, 2004) are just a few examples of the topic's complexity and uncertainty. Hermeneutics is a research practice capable of sitting somewhere in the fringes and muddy waters of AN, discovery, and family dynamics.

Last, hermeneutic inquiry was selected because of the responsibility it requires the researcher to have over the topic. In being responsible, researchers present their interpretations and understanding of the topic as incomplete. They also acknowledge that experiences can be interpreted in different ways. The hermeneutic way of seeing the world calls on researchers' humility, and general understanding that a topic can never be fully understood, because it was already in existence before the researcher was called to it.

Being Called by the Topic: The Address

Hermeneutic inquiry begins with an experience of being addressed. The world throws things at us, these things or topics may barrel towards us like they were loaded in a sling shot, or they can casually appear to us and then retreat like the waves lapping a sandy beach. The point being that rather than us choosing to study a topic, our topic comes to us and is personal. "An address is the feeling of being caught in some aspect of the world's regard, of being called or summoned" (Moules et al., 2015, p. 71). It is difficult to pinpoint a start and an end to a hermeneutic study, but if one had to set a place where the inquiry begins, it is often around the time the topic personally addressed the researcher.

"When a topic shows itself, *it haunts us*, because it also 'hides' itself" (Moules et al., 2015, p. 72, italics in original). This statement is striking, as it parallels my research topic. Eating disorders, particularly AN are insidious and sinister. Individuals with AN and EDs in general, refer to them as Ana or Ed, giving them lifelike qualities (Gailey, 2009). Of these qualities, they are sneaky and in a constant fight for power and control over the individual affected. Eating disorders hide deep within an individual, perhaps why these illnesses present as so difficult to treat (Hubert Lacy & Sly, 2015). When one is addressed by a topic, hermeneutics asks that the researcher suffer through the unknowns of the topic, putting what one believes to be true of the topic at risk, to be receptive from learning about the topic and potentially learning something that is surprising about the topic (Moules et al., 2015).

Positioning Myself Within the Research: My Address

Reflecting back onto my academic journey, it is not random that I chose to study EDs. The fact is that I could not escape them, I could not distance myself from important people in my life who unfortunately experienced one form of an ED or another. I have been addressed by this topic multiple times. The first event that stands out to me and has shaped the direction I have

taken my research was when one of my family members made the discovery that another family member had an ED. I was notified of this discovery by phone and was left speechless, wracking my brain for possible signs that I had missed in the months prior. The second event that was particularly powerful was the time it was discovered through way of family whispers that another family member had been hospitalized for months due to a severe, life threatening ED. This latter situation of discovery appeared to unfold over a period of months, and was not a sudden discovery like the first instance. Both times were equally shocking. Both times left me feeling useless. Both times stayed with me and replayed in my mind. However, what was different about these situations were my family's actions in response to the discovery. Professional help was sought immediately after one discovery, whereas while the other discovery slowly unfolded, the family did not race to find help until several months had passed, and in fact may have acted in ways that further enabled the ED.

Evidently this is a nuanced phenomenon. Clearly the discovery that your loved one has been struggling, often times suffering alone without bringing anyone else into their experience pulls on the heart strings of those who love them. With this address, I entered this research and sought to better understand the experience of parents who have discovered they have a child living with AN.

Aim and Scope of Hermeneutic Research

Hermeneutics is the study of understanding and interpretation of where our topic fits into language, culture, and history. In order to think hermeneutically, we must be open to the possibility that we may be changed as a result of understanding. Thus, the goal of hermeneutic inquiry is to answer questions like, *How might we understand?* and *How might we interpret the topic?* Hermeneutic research questions reflect that, as researchers, we come to a topic that is

already alive and that topic may have multiple interpretations. Since we show up to the topic once it has already been shaped, we join in with the topic as it moves forward, fully knowing that what has already happened or what is to come cannot be completely captured in interpretation. This is especially true of the exploration of parents' discoveries that their child has AN. These discoveries have already taken place and shape and are entirely unique to each individual, therefore, the aim of exploring *How might we understand these experiences of discovery?* is entirely fitting with the stance taken by hermeneutic research.

Hermeneutic inquiry requires researchers to engage with individuals who have experienced the topic, so that we might learn from them. The point of this inquiry is not to essentialize the phenomenon under study, as is the case in phenomenological research, but instead seeks to conserve the complexity and messiness of the topic (Moules et al., 2015). Phenomenological studies aim to describe and define the phenomenon, while removing the context that makes that topic whole. Hermeneutic inquiry aims to look at the topic from different angles, playing with the possible distinctive meanings that the topic can hold, and ultimately seeks to learn about the topic in its integrity, as a living thing (Moules et al., 2015). Rather than essentializing the topic to what it means to discover and isolate this experience to its simplest elements – time of day, what was discovered, response to the immediate discovery – to hermeneutically explore a topic means to search for the context, the whole yet limited experience of the individual discovering, what comes to mind about the discovery in the weeks or months after, or how the person making the discovery felt in the moment, for example.

Further, hermeneutic inquiry requires the researcher to understand themselves, and how they contribute to the interpretation of the topic. In this sense, Gadamer (1960/2013) advised that it is important to be aware of one's biases, so that the topic to be interpreted can present

itself in all its otherness. It is a logical fallacy to take ourselves out of the topic. Other research approaches lay claim to bracket out the biases of the researcher (e.g., Husserl's phenomenology), yet this is not possible. The idea of bracketing implies the researcher is capable and conscious of their limits and prejudices and by setting them aside he or she is able to become objective (Moules et al., 2015). Hermeneutic researchers argue this is not the case, as it is not possible to be aware of all our beliefs and judgements about the world; take the concept of aletheia for instance. Therefore, in hermeneutic inquiry the researcher is responsible for describing why the topic was chosen and how the researcher's own history, tradition, culture, and relationships play into their interpretation and in fact, fits in it.

Implications of Hermeneutic Inquiry

In defence against claims that hermeneutics is nothing more than an approximation, Gadamer noted "the very idea of a definitive interpretation seems to be intrinsically contradictory. Interpretation is always on the way" (Palmer, 2007, p. 240). Hermeneutic inquiry does not measure, quantify, describe, or generate theory, but rather answers questions that could have very well been answered differently (Moules et al., 2015). What this means is that hermeneutic inquiry provides understanding of a topic that cannot be ignored.

Hermeneutic research may yield any of three types of utility defined by Sandelowski (2004): instrumental, symbolic, and conceptual. Results of hermeneutic inquiry could result in change in one's practice, referred to as instrumental utility. For instance, clinical guidelines and education programs intended to educate families and the public in general about the stigmas associated with AN could be influenced by hermeneutic work. Further, hermeneutic inquiry could yield symbolic utility, meaning it could have persuasive power over stakeholders involved in a topic (Sandelowski, 2004). Hermeneutic inquiry has the potential to impact a topic and

show that the topic truly matters, requires more resources, or legitimizes the experiences of individuals involved in the topic. Last, hermeneutic inquiry can lead to a shift in values, or an ability to think differently about things, which is known as conceptual utility (Sandelowski, 2004).

Interpretations of human experiences, rules, texts, and relationships are immediately useful, in that they allow us to understand the world. Hermeneutics provides a reflection upon possibilities (Palmer, 2007). Hermeneutics implies a finitude about human being and human knowing, and makes clear that the past, present, and future are living things that have power over the topics under examination. Philosophical hermeneutics has been brought a long way since the 17th century, and with this modernization the theory has become more amendable to practice disciplines, namely counselling psychology and the complex inquiries researchers in this field undertake. To think hermeneutically, one must be open to different points of view, look into history, culture, and context, be cognizant of language and its universality yet finitude, and be aware and responsible of one's prejudices, all while acknowledging that a complete understanding of the topic is never possible.

Significance for Counselling Psychology

This research provides insights into the experiences and perceptions of those who are on the receiving end of discovering their family member has AN. These voices are pivotal in understanding the lead up to a disclosure or an eventual discovery, and could provide insight to the state of family functioning in the weeks or months prior to when AN becomes apparent to others. This research may also provide insights to how family dynamics and relationships might remain stable or change after the discovery. Currently, nothing has been published about this discovery process, therefore any and all findings will be a beneficial contribution to our

understanding of this complex phenomenon for both researchers, clinicians, and the families themselves.

As it relates to counselling psychology, this research sits within the gray areas, not finding a home in treatment, prevention, promotion, or education. This topic is important to the profession, because in the same way, counselling psychology has struggled to find a home and differentiate itself from other professional disciplines. A field that initially focused on career and guidance counselling (Robertson & Borgen, 2016), has undergone a transformation where an applied psychology specialization evolved. Not only is this research a significant contribution to the ED field, but it will also highlight the heterogeneity of counselling psychology's applied practice, research interests, and commitments to furthering the largely ambiguous field of AN. In the remainder of the chapter, I will present the research design that I utilized in my hermeneutic study.

Current Study

Participant Recruitment and Data Collection

After receiving approval from the Conjoint Faculties Research Ethics Board (CFREB), as well as permission allowing me to gain access to particular community organizations, I began recruitment in the Fall of 2018. Participants were recruited from (a) the Eating Disorder Support Network of Alberta (EDSNA) Facebook page and (b) the Calgary Silver Linings Foundation Facebook page. Electronic posters advertising the study were shared on social media platforms including Facebook and Instagram (Appendix B).

In order to participate in this study, participants must have:

- been the parent of a child who experienced AN (either AN restrictive or AN binge-purge subtype);

- speak English;
- have had a child between the ages of 12 and 25 at the time/s of discovery;
- confirm their child was cared for by a physician, if the child currently experienced AN.

Participants were not recruited to the study if:

- the discovery of AN happened after the child already had recovered.

Participants were asked to discuss their experiences of learning their loved one had AN, their relationship with that individual prior to, during, and after the discovery, and family experiences following the discovery.

Why anorexia nervosa? Parents of children experiencing AN, rather than another type of ED were recruited for this study. There were several reasons for this decision. First, losing a significant amount of one's body mass is a hallmark feature of AN (Gray et al., 2015). Weight loss is achieved and maintained by severely restrictive energy intake, strict adherence to rules regarding food, and can include regimented excessive physical exercise (Gray et al., 2015). These unique and severe features of AN may lead to parental discoveries that are distinctive from learning a child experienced BN or BED. Second, the clinical presentation, outcome, and treatment requirements for AN are different than BN and BED (APA, 2013). By sampling parents of children with AN, I focused my examination on a cluster of symptoms or experiences more characteristic of AN. Last, previous research on disclosing an ED has indicated that some individuals feel "too far gone" to hide their eating behaviours and weight from others (Williams et al., 2018). *Too far gone* might be in reference to one's body being too slim to hide the weight loss. By narrowing the focus of this research on parent's discovering their child has/had AN, we might better understand this too far gone reference, as again the unquestionable shrinking of one's body is hallmark of AN.

Interested individuals were invited to contact me, using the contact information provided in the recruitment posters. An initial telephone screening interview was scheduled with potential participants. The main purpose of this screening was to ensure parents interviewed represented the intended sample. It was not meant to diagnose an ED. The goal of the screening protocol was to establish that participants' children likely experienced AN, and not another ED. Despite some shared psychological features, EDs categorized within the DSM – 5 differ from each other in clinical presentation, outcome, and treatment requirements (APA, 2013). A general protocol for screening is displayed in Figure 1.

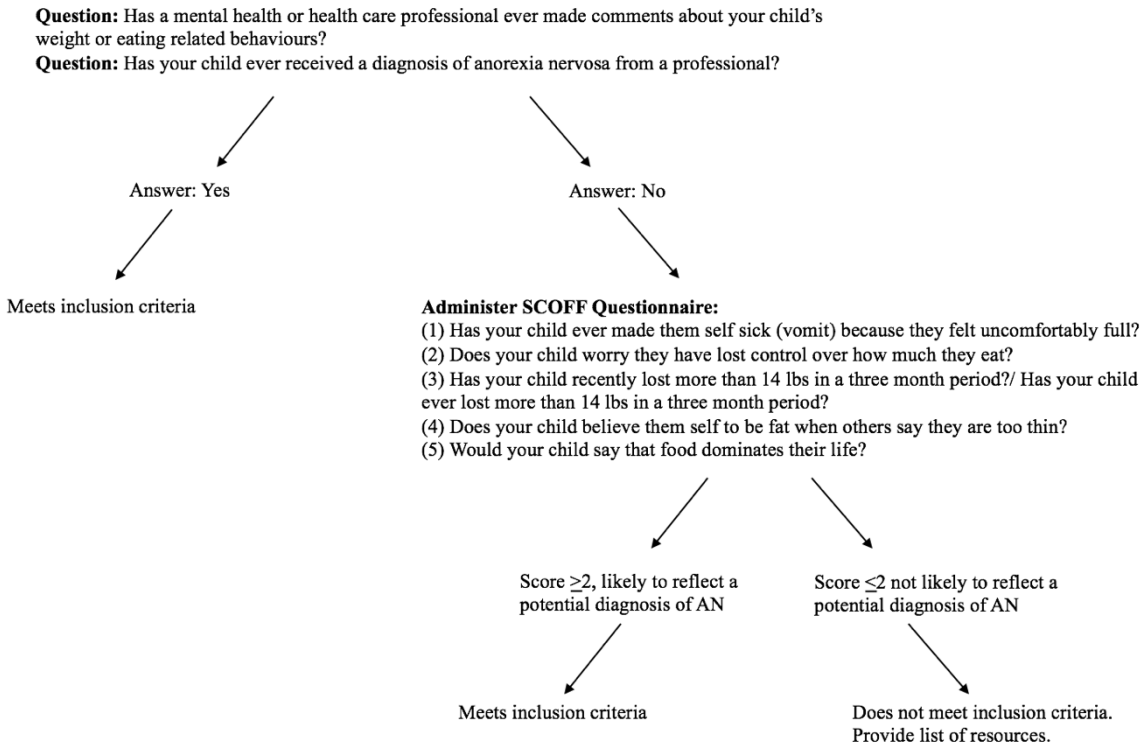

Figure 1. Screening interview protocol flow chart.

The screening interview progressed depending on the interviewee's answers. First, parents were asked broad questions regarding whether their child was ever diagnosed with AN, or if any professional (e.g., physicians, psychologists, mental health counsellors, nurses,

dieticians, dentists, et cetera) ever made comments about their child's weight or eating related behaviours. These questions were intended to solicit information regarding previous diagnosis or concern of AN. If parents answered yes, they met inclusion criteria for participation. Every parent who completed the screening interview identified that their child had received a diagnosis of AN from a professional either working in general medicine or at an ED specialty clinic. If parents had answered no during screening interview, I would have asked them questions that have been adapted from the SCOFF questionnaire, developed by Morgan, Reid, and Lacey (1999). The SCOFF was developed for non-specialists, to raise attention that an ED may exist. The SCOFF is highly effective in screening for EDs, and was designed to alert for likely cases, rather than to diagnosis (Morgan, Reid, & Lacey, 1999). One point is given for every "yes" that is answered. A score > 2 or greater indicates a heightened possibility of AN, thus participants with these scores would have met inclusion criteria. Participants' answers that did not reflect a likely case of AN, would not have been included in subsequent interviews, as they would not have reflected the intended sample. If participants did not reflect the intended sample, they would have been given a list of community resources, should they wish to look further into assessment, treatment, or support options. Regardless of the outcome of the SCOFF, I would have emphasized that the questions were not intended to provide a diagnosis, but rather to collect information regarding whether an ED might have existed. However, the SCOFF was not needed in this study because all participants told me that their child had been diagnosed with AN by either a psychiatrist at a specialty ED program or by their family physician.

Everyone who I conducted the screening interview with met the inclusion criteria for the study, thus no one was turned away. After the screening interview was completed, participants were invited to partake in face-to-face or telephone interviews. Selecting appropriate families to

partake in this research was an important requirement of hermeneutic inquiry, as not all individuals make ideal candidates for learning more about a topic (Moules et al., 2015). Hermeneutic inquiry seeks participants who can provide a full account of their experience and the topic under examination, therefore parents believed to be capable of providing thorough accounts were targeted.

I initially proposed speaking to six to ten families, as this sample size is consistent with hermeneutic research requirements (Moules et al., 2015). "Hermeneutics research is not validated by numbers, but by the completeness of examining the topic under study and the fullness and depth to which the interpretation extends understanding" (Moules, 2002, p. 14). Therefore, an acceptable number of participants is determined by how many accounts must be explored before a new understanding about the topic can be achieved.

Electronic recruitment posters remained posted in targeted social media sites until nine families were represented in interviews. In total, I conducted 10 interviews: seven interviews with mothers, one interview with a father (whose partner I interviewed separately), and two interviews with a mother and father together. This procedure and method of data collection has been carried out previously in the study of AN (Honey et al., 2006), where 48 interviews were conducted with individuals (daughters) with AN, both parents together, one parent only, both parents and daughter, et cetera and represented 30 families. This style of recruitment was intended to gather a range of experiences and account for various dynamics during the interview process.

Interviews took place in private rooms located within the University of Calgary, a participant's place of business, and over the phone. Participants had the option to choose to engage in the interview independently or together with their partner. This option was given to all

participants as it may have (a) ensured their comfort while speaking about a sensitive topic; (b) provided me with richer data as there might be more than one perspective and experience being shared; and (c) lead to a genuine conversation between those who were directly involved in the discovery, if the discovery involved multiple people.

Participant demographics. Participants' ages ranged from 44 to 61 years old (mean age = 52.6 years). Of the nine families represented in the interviews, seven were married, one was separated, and one was divorced. The average number of children participants had was 2.3. Eleven participants lived in Alberta, while one lived in New Brunswick. At the time of discovery, the average age of the child with AN was 17.1 years old, ranging from 13 to 21 years old. Of the nine families represented in the interviews, seven had a daughter with AN, and two had a son with AN.

Interviews. The interviews were considered unstructured in nature, meaning that I did not adhere to a set of pre-determined interview questions. This type of interviewing is consistent with the hermeneutic method in that researchers have an interview guide with general guiding questions (Appendix C), however are adaptable and allow for the topic to unfold organically and respond to leads in the conversation without being held to a rigid script (Moules et al., 2015). Given the flexibility during interviews, some interviews included questions such as: "Tell me about your experience of discovering your child has AN," and "When you look back on your experience of discovery, what did you first notice, what would you go back and tell yourself?" These questions were asked depending on the flow of the interviews. Regardless of if the interview guide was used, I asked follow-up questions and queried for clarification throughout the process to ensure a deep understanding of the topic and the participants' experiences.

I scheduled interviews to be staggered (i.e., one to three days in between interviews) so that I could have time to reflect and consider if there were leads I missed, or questions I had left unanswered. This method proved helpful, as between each interview, sometimes a new question would come to mind. While staying true to the topic and method of hermeneutics, I let discovery guide the interviews. Throughout the interviewing process, I played around with how my participants and I entered the conversation.

Data Analysis

Interviews were audio recorded, transcribed verbatim by me and a professional transcriptionist, and analyzed by me. While interviewing and transcribing, I coded and made interpretations of the data concurrently. Though coding was a way to organize my understanding of the topic and on-going conversations with participants, it did not refer to a process of reduction or eliminating variability. Rather, data analysis in hermeneutics requires researchers to think divergently rather than in terms of convergence and open up the topic rather than reducing it to single themes. Therefore, it makes sense that "hermeneutic analysis is a very deliberate attempt to listen for particulars of experiences and thoughts that are not based on repetition to authenticate their authority" (Moules et al., 2015, p. 119). This research approach seeks to complicate our understanding of a topic, because by doing so we move past a description of the phenomenon and we add realness, context, and counter examples, all for the purpose of understanding better. Interpretation in hermeneutics proves to be complicated work, as researchers must deconstruct and reconstruct the topic and their beliefs about it while also welcoming new possibilities. To assist with this latter task of bringing light to new possibilities, literature relevant to the data was also reviewed to assist with a comprehensive process, ultimately leading to a refinement of interpretation. At various points throughout this process, I

consulted with my supervisory committee and invited them to share their interpretations and insights on the topic, as doing so strengthened the credibility and trustworthiness of the interpretation.

Ethics

Informed Consent

After participants expressed an interest in the study, completed the telephone screening interview, and met inclusion criteria, we arranged a time within the next week to complete the interview, either in-person or over the telephone. For those living outside of Calgary, and therefore completing the interview over the phone, I emailed them the informed consent form in advance of our discussion. These participants were encouraged to review and sign this document prior to the phone interview. During the scheduled phone interview, I reviewed the form once again with participants. For participants completing an in-person interview, I brought printed copies of the consent form to our meeting and spent the first 10-15 minutes discussing the informed consent form and answering any questions (Appendix D). The consent forms provided a brief description of the research, purpose, benefits, and potential harms that may result from study participation. The last several pages of the consent form included a comprehensive list of crisis, mental health and ED community resources in Calgary, surrounding areas of Southern Alberta, and across Canada. Participants were encouraged to ask questions and seek clarification. Informed consent was signed before the interviews commenced. Due to the sensitive nature of the topic being discussed, it was made clear in the informed consent that participation was voluntary and consent may be withdrawn up until data analysis began (typically one month after the interview).

The following precautions were planned in the case of distress or crisis during the interview. Prior to completing interviews, I communicated to all participants that if they wished to stop, their request would be honoured and the interview would end immediately. In the same vein, due to the complexity of the topic, participants were aware that they did not have to answer every question asked of them. In terms of safety, I monitored verbal and nonverbal signs of distress. Before interviewing began, participants were informed that in the case that I determined the distress to be too great, or if the participant expressed they were not feeling comfortable, the participant would be asked if he/she/they wished to take a break or discontinue. Further, I had planned that in the case that during the interview I learned that the child with AN was in imminent danger, I would refer to the study crisis protocol. The crisis protocol outlined steps to be taken in an emergency situation (i.e., parents/guardians to call 911, go to emergency room, consult physician; Appendix E). Throughout interviews, none of my participants demonstrated any signs of serious distress, and all children with AN were not currently in critical danger, and were under the care of professionals, thus the abovementioned distress and crisis planning was not utilized in the current study.

Due to the sensitive and complex nature of this research, every precaution to ensure confidentiality was taken. Prior to starting interviews participants were asked to choose a pseudonym for themselves. This name was used in transcripts and interpretations used in final writing pieces in replacement of the participant's actual name. The same process was followed if participants mentioned the name of their child with AN. In addition to these precautions, audio and transcription files were saved within password protected files within a password protected computer for additional security. Further, the professional transcriber signed a confidentiality agreement form, noting that she would not reveal any of the contents of the audio files or reveal

the identities/names of participants. No paper documents were saved, aside from paper consent forms, which are stored in a locked filing cabinet. As mandated by the University of Calgary, I will keep all electronic files on my computer for five years, and after that time all files will be deleted from my computer and hard drive.

Compensation. Upon completion of interviews, parking expenses incurred by participants parking at the University of Calgary during interviews were reimbursed.

Benefits of Research

Though interviews focused on events or periods within participants' lives that may have been shocking, intense, and/or frightening, participating in this research may have yielded several benefits. First, participants may have benefited from sharing their experience with another person who was non-judgmental and unbiased towards their personal discovery of a child experiencing AN. Family members who may not have responded initially to the discovery in supportive ways might feel guilty for their actions, and participating in an interview may have served as a cathartic way for these individuals to share their experiences. Second, literature demonstrates that families of a child with AN play an important role in the recovery from the disorder (Treasure et al., 2008; Zabala et al., 2009), therefore by participating in this research these families are contributing to the advancement of knowledge. Participation and the sharing of their experiences may help other families in the future, and ultimately enhance the care of those with AN. Upon finalization of this research, interpretations will be shared with participants. Doing so may demonstrate to participating individuals that their involvement was a meaningful contribution to better understanding another complex factor about AN. Finally, participating in this research may be beneficial simply because it will offer participants an

opportunity to discuss EDs, AN in particular, and their beliefs and knowledge of this topic, hereby increasing their mental health literacy.

Degree of Risk

It is important to note that the participants of this research were not children with AN, but were the parents, thus representing a degree of separation. The degree of risk for this research is low, as the probability and magnitude of potential harm is unlikely. While unlikely, during interviews participants may have experienced mild psychological distress when asked to recount the experience of discovering that they had a child living with AN. Recalling these memories may have been difficult for individuals for a number of reasons including (a) feeling sympathy and/or helplessness for their child, (b) experiencing guilt for the way in which they responded to the discovery, and (c) feeling discouraged or concerned about their child's future prognosis with AN.

Summary

Hermeneutic inquiry is a unique method, that lives, evolves and honours the history, universality, and language of a topic. The interviews and emerging interpretations come to mean something to those involved, in other words, at the heart of hermeneutic inquiry, there is something at stake. As Gadamer explained,

> Discussion bears fruit. The participants part from one another as changed beings. The individual perspectives with which they entered upon the discussion have been transformed, and so they have been transformed themselves. This, then, is a kind of progress – not the progress proper to research but rather a progress that always must be renewed in the effort of our living. (Gadamer, 2007, p. 244)

As hermeneutic inquiry is a unique method that easily stands apart from other qualitative approaches, so too does it differ in writing style. In the following chapters, I offer my findings section, comprised of several distinct chapters on discovery, the fracturing capacity of AN, aletheia: revealing and concealing, and the unspeakable nature of EDs. Hermeneutic findings chapters often include relevant literature to support interpretations, hence resembling chapters that readers may distinguish more traditionally as discussion chapters. In the following chapters, I offer my interpretations of how parents come to discover their child has AN.

Chapter Four: Discovery

> *I went in and [my son] is literally in a ball on the floor and is just bawling… she says your son is within hours of dying. She says, either you take him to the [hospital] now, or we put him into an ambulance and take him. I'm like standing there. What are you talking about?* (Betty)

Utter shock, a sinking feeling, a wave of relief, confusion, guilt, and complete helplessness. These are some of the emotions that parents cycle through when they discover their child has AN. Few things in life prepare one to find out that their child has been starving themselves for a prolonged period of time. Even fewer things prepare parents to learn of how their lives are about to change and how they will be required to let go of all expectations. In this chapter, I will describe the discovery process of learning that one's child has been experiencing AN. I offer topics including the weeks and months marked with tension and obvious changes within the child and family, the official diagnosis, the isolation experienced afterwards, what parents consider to constitute the word "discovery," and the inherent ambiguity involved in all stages of discovery.

Discovery – How do Parents Make Sense of It?

Throughout communicating with parents, the meaning of "discovery" was assumed. When asked to explain their discovery, all parents without prompting began sharing stories of intentional self-disclosures by their children, confrontations between themselves and their child (both before and after the discovery), and a prolonged period of confusion and tension. It was not until I paused in a moment of reflection that I realized I had not explicitly asked what exactly discovery meant. This question opened up the site of inquiry to a much larger situation, described as a continual unfolding. It seemed that the longer I spoke to parents, our

conversations offered us all moments of reflection, something that these parents had not been afforded previously.

It appears as though the majority of parents whose child has/had AN do not spend a great deal of time reflecting on the discovery period. They recall the consuming guilt and the agonizing period leading up to anything being officially confirmed, but when asked to simply reflect on the "discovery" period, most parents struggled. When AN is suspected by health professionals, there is a time sensitive focus for assessment, admitting youth to hospitals, re-feeding, and engaging in programing resulting from literature encouraging fast action and treatment following the onset of AN (Kempa & Thomas, 2000; Treasure & Russell, 2011; Van Holle et al., 2008). As recovery from AN becomes more unlikely the longer the illness persists (Van Holle et al., 2008), this means that the discovery process and a time for parents to absorb and understand what is happening is often overlooked, as parents race and are pushed into the next steps typically by health providers and from information found on the internet. It seems that discovery is critical for parents at all phases of their child's experience with AN, but especially critical during the early stages of recognition and interactions with health professionals. There appears to be a seemingly endless supply self-help and/or parenting books available on how to help one's child with an ED, all suggesting immediate action, but never suggesting that parents take some time to reflect on the massive changes and fears that their family is experiencing. The term discovery means to find or learn of something for the first time (Merriam-Webster, n.d.). When taking in new information, especially the shocking realization that one's child has developed AN, a period of time for parents to reflect is not available. Therefore, meeting with parents and discussing the discovery, how that affected them, and what it meant served as an intimate joining and reflecting on the pain this period of time entailed.

Discovery was described as:

- months of noticing changes in a child's mood and behaviour, yet not being able to place one's finger on it;
- watching one's child losing weight, isolating themselves from family, friends, and activities;
- feeling as everyone in the family was "walking on eggshells," watching what they said as to not further irritate or anger the child;
- confusion with what was happening and doubting the self that anything was different;
- reaching out to trusted others and asking if they had noticed anything different;
- arranging a series of medical and mental health consultations where parents were searching for answers;
- the official diagnosis of AN; and
- the realization of what AN means, the trajectory of the illness, and the possibility that AN could be life-long.

This list demonstrates the multifaceted and prolonged experience of discovery for parents. The experience has similarities to an unravelling ball of yarn. The ball begins tightly wound, and as parents begin noticing changes in their child, as the concern mounts, the ball of yarn unravels at a slow but steady pace. As medical professionals become involved and it seems there is more clarity and answers for parents, the ball continually becomes a messy complication, only to become more entangled when realizing the implications that AN has on the child and family in the short and long term. To complement this description, one parent shared how she made sense of the continual unfolding of discovery:

> Unravelling in our family right, or unraveling the family patterns… then just unraveling the way that you thought everything was working is not the way it was working. So that that realization is a real, it's like, the bottom of your world drops out right, is like the elevator dropping, and you're like, "Okay, now we're in the basement." "What do we do?" "How do we figure this out?" (Lynne)

Due to the complicated nature of AN (Williams et al., 2018), the discovery is a prolonged experience. Learning one's child has AN is not easy to comprehend. In fact, learning one's child has AN is a sharp contrast to learning a child has a broken bone for example. In the case of a broken bone, the diagnosis is clearer, access to services and treatment begins immediately, and the explanation of how the arm broke is irrefutable. In the case of AN however, these points of recognition, intervention, and prognosis are ambiguous. There are so many layers to be peeled back to get at a basic level of understanding that parents find themselves in a prolonged period of uncertainty, unequipped with information.

Ambiguity

As taken up in an earlier publication (Williams et al., 2018), ambiguity refers to understanding a concept, word, or expression in two or more ways (Merriam-Webster, n.d.). Uncertainty, doubt, and hesitation are closely related to the concept of ambiguity, all pointing to the tendency to wander, waver, and change. Perhaps then, ambiguity can be thought of as the vehicle that carries the discovery of AN. In other words, ambiguity carries the weight of this topic (ironic in itself). Throughout the many phases individuals with AN go through (e.g., discovery, recognition, diagnosis, treatment, recovery), ambiguity makes itself known. Ambiguity is not merely felt by the individual with AN, but also takes up space in the lives of others, namely professional helpers, caregivers, and families. The ambiguity marking the many

phases is cause for concern for practitioners providing treatment to individuals with AN (Adlam, 2015; George, Thornton, Touyz, Waller, & Beumont, 2004) and is troublesome for family members and friends in supportive or caregiving roles (Craigie, Hope, Tan, Stewart, & McMillan, 2013; Voriadaki, Simic, Espie, & Eisler, 2015). "At all points throughout the course of AN, ambiguity is not far away, it is not separate from the experience but rather a part of it" (Williams et al., 2018, p. 4).

Ambiguous discovery. To be human means to wrestle with ambiguity. It surrounds us, it engulfs our world, maybe it encompasses even further out beyond our understanding. The point being, there is no escaping the uncertainty of being alive and this is terrifying. To constantly be stumbling around ourselves and our understandings is exhausting. Ambiguity tests our capacities to tolerate the unknown – in the context of AN, ambiguity clouds the discovery, leaving parents uncertain of their child and of themselves. As De Beauvoir, the French existentialist philosopher wrote:

> To attain his truth, man must not attempt to dispel the ambiguity of his being but, on the contrary, accept the task of realizing it. He rejoins himself only to the extent that he agrees to remain at a distance from himself. (1948/2015, p. 12)

Profoundly, De Beauvoir captures a universal fact of life – no one knows what is to come and rather than chasing a reason or looking for absolutes, the only way to live in this world is to realize that this is the condition of being human. Perhaps this is the reason why parents discovering their child has AN is beyond comprehension for many. There is something ambiguous about the nature of AN that causes parents to struggle and for terror to set in. As one mother shared:

> I'm thinking, "Oh my God," I thought I knew. I thought I knew. I didn't really, what it all entailed, and what was about to come and how it would throw her life into disarray, and our life into disarray, and I didn't even know what to anticipate, what to expect, what was coming, what was happening… At the time she tells you that, my whole world fell apart. I cried. (Hope)

As I write, read, re-write, and re-read this interpretation I am brought back to my own experience with ambiguity and its ability to unsettle me, leading me to question my convictions. While conducting interviews with parents, I was also applying for psychology residency positions across the country. The night before the highly anticipated "Interview Notification Day," I received a rejection email from a site on the other side of the country. Due to the time difference, I received the email at the early evening hour of 9PM in Calgary. The arrival of this email caught me off guard. While I had planned to enjoy an evening of distraction, the news of rejection and failure threw a wrench in my evening plans. The rejection brought uncertainty and fear with it. That night I cried myself to sleep, griped by fear of the unknown and what would become of me and all of my efforts to date. I had aspired to be a psychologist for as long as I could remember, and my future ambitions were under the order of gate keepers. I spent the rest of the evening convincing myself I was not competitive enough and that I had been too optimistic. Ambiguity was in charge, leaving me in the backseat with absolutely zero control. It was not until the next morning when I opened my emails to learn of my interview fate that I was able to feel settled once more.

Although this recent account of uncertainty seems superficial compared to the ambiguity that parents of a child with AN face, situations and things that are highly ambiguous have a tremendous power over people, with the ability to change how they think, feel, and behave.

Ambiguity has been defined as "the state of being uncertain" (Cambridge Dictionary, n.d.), inevitably causing discomfort and confusion. Even the most rational and pragmatic people fall victim to situations they have no control over. A simple Google search reveals how wide spread and uncomfortable ambiguity makes the masses feel, with advice in the form of the following online articles: "3 ways uncertainty and discomfort help you grow in life," "tips on tolerating uncertainty," and "uncertainty is more painful than the pain itself," to name a few, from Psych Central, Forbes, and Psychology Today websites. Evidently, ambiguity is a construct that people are aware of, and perhaps know there is nothing to be done to counteract it, yet even with this knowledge they react in ways that heighten anxiety and fear of the unknown anyways. Maybe this is a condition of being human.

Discovery lingers. Discovery extends past the day parents are informed of the diagnosis. Though it may be automatic to think that after the diagnosis has been delivered, parents are onto the next assessment or treatment phase of their journey with AN, the discovery process still lingers. In many cases, the process of diagnosis and admittance to the hospital was such a hurried process that parents were left behind, left in the darkness with no knowledge of what exactly AN meant. As the days and weeks passed, seeing their child being attended to by professionals and watching their children adamantly resist the re-feeding process, many parents remained unaware of what was happening, and only until they sought resources and attended parent workshops and support groups did they finally feel they had a grasp on AN, and thus their period of discovery came to an end. Accordingly, discovery also entailed education. Parents yearned for more information, "please teach us, like tell us what we are doing" (Betty), one mother shared. A tone of desperation was apparent in her voice. The discovery experience is marked by a parent's frantic search of trying to understand what one's child is experiencing and

if they can help in any way. Aside from education, discovery also consisted of recognizing and fully understanding the chaos that AN would bring into their family's life. Being told that one's child has AN is heavy (ironically), but then seeing first-hand how AN torments one's child brings the discovery full circle – it makes it complete. Nearly every parent recounted unique stories and realizations that happened during their discoveries that foreshadowed what they were dealing with, adding context to the diagnosis delivered. One mother shared:

> And every time we would go back [to the hospital] she would lose more weight. And they would say whatever. "Your heart rate is this." And it would scare [daughter]. And when we'd leave, like I would be bordering on crying as I'm driving away. "Like [daughter] what are you doing? You just have to eat." She's like, "I know, mama. Let's go right now… I'll eat, I'll have a Boost." And she would go home, and you know, eat a lunch or whatever and you know by after school, by dinner, it would all be gone again and she wouldn't eat. And so, it would scare her, but by that point it was, things were too far gone. (Elizabeth)

Realizing how far gone, how deep the claws of AN were sunken into her daughter was a part of this mother's discovery. Seeing how much her daughter wanted to please her by eating yet was overcome with fear only a few hours later was a realization that her daughter was in extreme danger. Discovery requires context.

Period of Change

A lingering stretch of time marked by parental suspicion that something was not quite right is a hallmark feature of discovering one's child has AN. The sense that something was different in one's child was apparent, yet the sources of these observable changes were not available to parents, "You know that something's off and you want to help her, but you don't

know what. You don't know what you can do" (Dawn). When describing her daughter's sudden change in attitude, one mother shared,

> All of a sudden, it was like, "why is she spending so much time in her room?" "Why is that every time we ask her something, she barks at us?" It was always little things like that. Always in the back of my head, "What set her off this time?" Or "what's wrong this time?" (Taylor)

A state of mental uneasiness, unrest, and uncertainty was experienced. The apprehension that filled parent's lives during the time leading up to the discovery and shortly afterwards was evident.

Webster Merriam dictionary offers context to the term *uncertainty* in that it "may range from falling short of certainty to an almost complete lack of conviction or knowledge" (n.d.). The idea that a parent can be in tune with their child and almost positive that something serious is going on, yet not have any idea of what exactly is occurring is painful to imagine. This image calls to mind the saying "ignorance is bliss," an idiom referring to people unaware of a problem are free from worry about it. This is the opposite for parents who have felt that something has been happening for months yet cannot grasp or make sense of it. A couple recalling the nine-month lead up to discovering their son had AN explained, "when something is wrong in your house you definitely know. But we didn't know what" (Ritch). Parents only have access to tangible signs, which include their child's behaviour, mood, nutritional intake, and weight. Though observing these outward signs may appear to be obvious red-flags to those on the outside, to these families, seeing these tangible factors in the absence of an understanding or root cause keeps them in the dark, unaware, unable to grasp at the truth.

"I Can't Tell Anyone" – Isolation Following Discovery

Along with the shock and fear that accompanies the discovery, parents also experienced isolation. Though parents may have the support of their partner who is sharing their experience and concern for the child, others outside of this circle are kept at a distance, at least initially for many parents. Maintaining a distance from others served many reasons, some including, wishing to respect a child's request for privacy, a strategy to minimize questions from others, a parents' belief that their child would recover at a rapid rate and reaching out to others for support would not be necessary, and a form of identity protection. When asked to explain her support network during the discovery, one mother explained:

> It's very isolating. You know, at the very beginning it was a "I can't tell anybody" because I'll have it wrapped up anyways, so what was the big deal in telling everybody. But I think that, for the longest time, I didn't really tell anybody and then your whole world becomes consumed with it… and for a long time I didn't tell anybody not because I was ashamed of it but just because it was so consumed every other part of my life and I just wanted to go and just be me and not have to talk about it… (Lynne)

Anorexia nervosa and the knowledge of it interfered and consumed parents' lives and how they saw themselves in the world. The word *consumed*, may shed light onto these parents' experiences. The Merriam-Webster dictionary defines consumed as "to do away with completely; to use up; to eat or drink especially in great quantity; to engage fully" (n.d.). There is something ironic, yet perfectly fitting given the context. First, individuals with AN can be thought to be dwindling away both physically and psychologically due to their lack of nutritional consumption. Meanwhile, parents are observing as their child cannot eat a morsel of food without self-hatred. These parents' lives are taken over, totally held captive as the AN engulfs the family or what used to be of it with its ravenous appetite. A parent's daily routine becomes

focused (if not completely) on their child's AN. Work commitments are postponed or modified for some, the care of other children no longer feels equal to that of the attention placed towards the child with AN, and standard routines of life once never questioned become a war-zone, like meal times, participation in extra-curricular activities, and family gatherings. In these ways, AN consumes parents' lives, taking over their identities, and forcing their focus that was once dispersed between various values and passions onto their child with AN.

By keeping the discovery hidden from others, parents were able to protect little parts of their lives, thereby leaving them untouched by AN. It seems as though once others discover what parents are going through with their children, the situation wraps around their identity as parents, making it very difficult for others to think of them as they once did – before the AN existed. By keeping some people unaware of what was unfolding at home and within the family unit, some parents were able to preserve their image as a parent without a child with AN – a parent who was not dealing with a crisis in their life and in their home.

Isolation may be amplified when a parent's grief is disenfranchised or deprived. When AN is kept private within the immediate family, this leaves some parents without an outlet to share their loss, and the privacy their child requests may feel like a burden to carry. The image of a heavy sack tied up and thrown into a body of water comes to mind. Parents are holding onto the knowledge that their child is experiencing a gravely serious illness and have been asked to keep this information to themselves. The longer the secret is kept, the heavier the sack is and, as additional information builds regarding the discovery, their child's trajectory, and their understanding of AN, the deeper the sack falls in the water.

Parents, not partners. Contributing to the isolation is the challenging navigation of partnership within couples. Discovering one's child is experiencing AN tests the strength of

partner's solidarity, commitment, and cooperation. For some parents, the discovery and following stages were tackled in unity, with parents supporting each other and knowing that when one was close to the verge of collapse, it was the other's turn to step in and care for the child with AN and also the rest of the family. For others, however, the discovery that their child had AN added enormous stress to the relationship and was noted partly as a reason for parents' separations (temporary and permanent).

It seems obvious that the development of AN within the child and within one's family would have an impact on relationships within that unit. Without expectation or preparation, AN was presented to the family as its new preoccupation, requiring full time attention. This change requires a settling in period where individuals involved figure out their roles and corresponding actions. In some partnerships, this transitional time did not end in resolve, and parental roles became fractured, with one allocated or believed to be the primary caregiver without a mutual agreement that that would be the case. Most times when there was disagreement between partners, it was typically mothers who bore the responsibility, placing an enormous pressure on this parent to fulfil their role, while in most cases, doing this while still taking care of the rest of the family. These siloed parenting roles led partners to feel like they were going through the discovery alone, as one mother shared:

> My role was to do all of the discovery and stuff like that and then he would come, like he was very good if I said you know "when you do a family session you need to do this, we need to do that," whatever. So, he would come along, but he didn't take any sort of a point on anything which was consistent with how we did everything in our marriage. (Lynne)

In addition to the distinct roles parents felt forced to take, the perception that the other parent did not understand AN or mental illness more generally caused rifts between partners. It seems that when one's child is facing any kind of immediate danger, parents take it upon themselves to learn about the condition, in order to better support their child; this however was not the case in all families with children with AN. Again, mothers spoke about the tensions that AN had created between themselves and their partners and noted that some fathers' inabilities to understand mental illness or the gravity of AN was beyond frustrating and, in fact, harmful to their relationship. Mothers found themselves having to educate their partners, telling them that AN was not a choice, was not a phase their child would grow out of, was not as simple as just eating, and was in fact incredibly serious. Essentially, some mothers had to convince their partner of the severity of the situation, causing an enormous amount of irritation and disconnection between the pair. When describing her relationship with her husband, one mother shared:

> It's created a lot of frustration, isolation. You feel like you're a single parent, let me put it this way. And in some ways, I have stopped expecting him to be involved and engaged, and then there's no frustration there anymore because I stopped expecting it. (Hope)

Mothers may experience psychosocial loss more than fathers, in situations where fathers deny or cannot grasp the severity of AN, or who do not understand mental illness. As Doka and Aber (2002), two grief and loss experts explained, when an individual faces an ambiguous loss it complicates the grieving process, as that loss might not be shared or acknowledged by others. Learning one's child has AN is ambiguous in the sense that the child has not died, yet there is still grief over the situation and the uncertainty moving forward. In these relationships, if parents are together, mothers may feel the need to supress their grief for the child, as they likely would

not receive the support they crave from their partner, thus causing them to feel more alone in their experience of caregiving and adjustment.

A Parent's Intuition

Watching one's child undergoing changes where the source is unknown is cause for alarm for parents. Noticing that something was off in their child caused parents to enter a state of constant observation and vigilance – acting like gate keepers to their children, yet not having the privilege of their child's inner world. One father shared, "It was horrible because you're watching somebody decline in front of you and you're thinking 'I should stop this, but I don't know how'" (Ritch). Through conversing with parents, it became clear that in the months leading up to the discovery, they experienced periods of certainty that their child had an ED, or even cancer, to periods of hesitation that anything was wrong. During these ambiguous periods, parents may have engaged in a visual phenomenon known as edge induction – where the mind fills in visual gaps in a scene or landscape that is hard to interpret (Brown, 2010). While lost in the confusion of what was happening, parents try to make sense of their reality as best they can, which means filling in the gaps with the answer most logical and available to them.

Relatedly, memories of the kilt I had to wear as part of my school uniform comes to mind, in the sense that the fabric was pleated, meaning there were pieces of material never visible to the eye. As the fabric was blue, green, and black plaid, one had to assume the hidden fabric was the same colour scheme and pattern, however without cutting the stitches, there was no way of confirming this. This is an easy assumption compared to searching for the answers of what is happening to one's child with AN, however using a pleated kilt as a visual anchor – parents looking for the whole story are only able to observe the outside pleats, left to guess what is happening in the time and space between.

Parents also asked others if they had noticed any changes in their children. Parents questioned their inner gauge on their children, yearning for consultation. When changes have been occurring for a period of months, it may be difficult for parents to be as sure as they once were that things were different. Physical changes are more noticeable and immediate to individuals not spending as much time with that person, perhaps why some parents checked with others. One mother explained:

> As soon as it got to a point where … As I put all of the pieces together, I was talking about it to anybody and everybody who would listen, because I needed to know if you were seeing … You know, for example, are you seeing the same things that I'm seeing? So, I had conversations with his dad. I had conversations with my parents, my ex's family members – his mom and sibling, my girlfriends who had seen him over that time span, and not noticed all of the behaviours, of course, but noticed the significant drop in weight and were worried that, honestly, he had cancer. (Donna)

These uncertain phases and asking others for their input were amplified by medical and mental health professional's opinions on the matter. After periods of hyper-vigilance of their children, many parents scheduled appointments with their family doctors or walk-in mental health consultations to discuss what they had witnessed of their child. All initial appointments occurred without their child being there, and most happened without their child's knowledge. These appointments speak to the torturous uncertainty parents experienced and demonstrate the lengths parents went through to find the answers they were desperate for.

In some cases, professionals confirmed the parent's suspicions and asked that the child be brought in for immediate assessment. In these instances, parents felt relief and validation, as for all of those months when they felt something was off, there was, and it had now been confirmed

by someone with authority. Though there was concern for what the future held for their child, these instances also brought relief and hope. Parents no longer had to be solely responsible for the care of their child. The confirmation from professionals also strengthened the parents' beliefs in themselves regarding how well they knew their children. In a way, this confirmation acted as a badge of validation. However, for every time parent's concerns were validated, they were also dismissed by health professionals, leaving parents to feel even more uncertain – being convinced there was something wrong, having one's child deny it, and now having a health professional not taking it seriously either, leading the parent right back to where they started – ambiguous terrain. These interactions caused parents great unrest and led them to question their intuitions. One participant shared his and his wife's turbulent experience with health professionals when trying to determine what was wrong with their daughter:

> The nutritionist said, "she's thin, but not unhealthy." What it did, it gave my wife and I the feeling of "okay maybe we are wrong." It was somebody else that we were hoping would say "okay we have a real problem here." All of a sudden you start second guessing this grand plan that you've got here. It came in waves. Go see the nutritionist, she gives us that answer, and now, "oh my God, are we over reacting?" To then, all of a sudden saying "no we aren't over reacting." Then we knew we had to get some help. (Pablo)

Parents at this stage are looking for reassurance and help from professionals to figure out what is happening to their child. Parents rely on professionals to provide accurate information and are consumers of discourses that place trust into doctors' hands. To be caught in such an ambiguous situation understandably makes parents uneasy, and those who are dismissed by professionals are sent back into the hyper-vigilant and self-questioning stages of discovery. One

couple explained that after months of watching their child's weight drop and observing his nutritional intake dwindle, they convinced him to accompany them to the doctor's office, only to be told that he was in perfect health. The tone in the mother's voice after sharing this interaction was beyond frustrated and deflated, and she stated that immediately she knew that the doctor's response would put her back several steps with her son, with whom she was already struggling to connect. Experiences like these are detrimental to a parent's progress in identifying what is happening to their child, and also to their belief in themselves as competent parents, in tune with their child's needs.

Diagnosis Makes it Real

During conversations with parents, reflecting on transcriptions, and meeting with my supervisory committee, I was struck by the significance that a diagnosis held for parents. As my supervisor (SRM) insightfully pondered, *for some reason, diagnosis makes it real*. This comment made me think about the language parents used throughout our conversations, the words emphasized when they reached out expressing interest in participating in my research, and the special importance they placed on diagnosis during the screening interviews (e.g., *she was diagnosed when she was 14,* or *hmm it's hard to say, he'd been sick for a while but was diagnosed with anorexia when he was 19*).

It was always my intention to include both parents of self-identified youth with AN (meaning they were not required to have sought a diagnosis or treatment) and parents of youth diagnosed with AN. By including parents of children believed to have AN and children diagnosed with AN, I attempted to hear from a sample of individuals without the bias of the medical model setting limits to who could speak to the experience of discovery. However, it seems that the medical model's dominance is nearly impossible to avoid, as parents used the

term "diagnosis" like a badge of authentication. Though what their child was experiencing for the weeks or months leading up to their assessments and eventual diagnosis was real, the concept of AN was not (in many parent's eyes). Western culture privileges diagnosis. Until an authorized professional has uttered the words *anorexia nervosa*, a parent does not believe their intuitions, or at least does not give themselves credit for thinking it was an ED. The action or process of diagnosis speaks to parent's (un)knowingness, discounting a parent's suspicions until there is something "official" on which to hold.

Allen Frances, an influential American psychiatrist, has written extensively on the impact that the DSM – 5 has had on the world of psychiatry, but also on the medicalization of ordinary life. In his book titled, *Saving Normal* (2013), Frances wrote about the power the "bible of psychiatry" holds. He also traces the concept of labelling back in time to when Shamans practiced healing, long before psychiatrists or psychologists existed:

> Abnormal behavior has always threatened our survival because we are so dependent on trible harmony. We need a name and an explanation as a way of gaining control over actions that threaten the individual and the social group (whether these occur on the savanna or at the office). Labeling was and remains an important way of reducing uncertainty and providing a sense of (often false) mastery. Finding patterns helps sort untidy experience into manageable units – an inexact or incorrect name or explanation for mental disorder beats having none at all. (2013, p. 35)

Attaching a name to a set of abnormal behaviours (abnormal compared to how the individual was previously) eases the anxiety of others. Thus, maybe this explanation sheds light onto why diagnosis, or receiving a label makes it real for parents. The same considerations have been

given towards why diagnoses hold so much power in the context of life-threatening illness such as acquired immune deficiency syndrome (AIDS) or cancer:

> Until the actual diagnosis, no matter what the expectation, suspicion, or fear, there is always a chance that the client's self-diagnosis might be mistaken. The lump may yet turn out to be a benign cyst, the rash to be only a minor problem. However, this changes at the moment when a diagnosis is rendered. Here the client's worst fears may be realized and the person is forced to recognize that he or she is now either in a struggle for life or an inexorable slide toward death… It should be recognized that the time of diagnosis is often not a single moment, though it may culminate in that moment when the diagnosis is spoken. Rather, it is a process unfolding over time in which a person experiences various tests or procedures during which different hypotheses of illness are advanced and sometimes discarded. (Doka, 2014, pp. 135-136)

Evidently the unfolding of the discovery is also true of receiving a diagnosis. Until the words are uttered, the mounting suspicions could amount to nothing. Maybe not believing something is real until it has been confirmed by someone with authority is a method of protection – an armour meant to keep the individual calm until there is legitimate reason to be concerned. This explanation makes sense and explains (at least partly) why receiving a diagnosis makes AN real to parents. However, there is still something about the power a diagnosis holds and how exactly a diagnosis gained its power and reputation that needs further examination.

The power of the DSM. What about the DSM gives AN power in parent's eyes? It was real before a diagnosis, but something changes and becomes more pressing once health professionals become involved. The DSM is considered the final word by many. It holds power. First published in 1952, the DSM listed and described a range of mental disorders reflecting

Sigmund Freud's psychodynamic theory – namely that mental disorders were a product of conflict between internal drives (e.g., "anxiety as produced by a threat from within the personality"; Adam, 2013, p. 417). The second edition of the DSM published in 1968 reflected similar ideas. It was not until 1980 in the third edition, influenced by European psychiatrist Emil Kraepelin, that mental disorders were recognized as separate syndromes, with causes and symptoms unique to each classification (Adam, 2013). Thus, the DSM – III changed the field's thinking and conceptualizations of mental disorders that have remained strongly upheld by dominant figures in psychiatry since. As the decades passed, the DSM – 5 was published in 2013, still reflecting a categorical approach to understanding and diagnosing mental disorders (Adam, 2013). This version (English version), contains approximately 1000 printed pages and is a foundational text used by psychiatrists, scientist-researchers, and is also a required reading for all graduate students in psychology and other mental health related programs. When considering the evolution and importance placed on this manual throughout our recent history, it is not surprising that parents perceive that AN gains a significant more amount of power once the DSM becomes involved.

Summary

Taken together, discovery is complicated. It is multifaceted. Discovering one's child has AN is marked by a period where parents are uncertain, yet the tension within the family unit is undeniable. Discovery is also comprised of learning of a diagnosis, which for some reason heightens parents' anxieties and promotes action, saying something about the power of medical diagnosis in this situation. Concurrently, discovery causes some parents to isolate and question themselves and challenges their beliefs about their parenting practices. Evidently, discovery becomes more salient than the Merriam-Webster dictionary suggests – it is a dynamic

phenomenon filled with uncertainty, discomfort, realization, changing expectations, family adjustment, and continual unfolding.

Chapter Five: The Fracturing Capacity of Anorexia Nervosa

"Your life falls apart around you when this is what's going on in your brain… there was something seriously wrong, and then the decline was so rapid. The weight just was falling off of her" (Gillian). All of the parents interviewed expressed that their lives were forever changed by the discovery of their child's ED. The sense that life was a certain way before the arrival of AN, and life was different after AN was echoed in discussions, with parents referring to life pre and post AN. After the discovery, life comes to a grinding halt. The world and one's place within it stops, forcing any plans for employment or leisure to slow down and take a back seat to the organization and coordination of everything revolving around the child with AN. Anorexia nervosa was spoken about like a destroyer, a monstrous force that wreaked havoc on families, parent-child relationships, and romantic connections and parenting roles between partners. In this chapter, I offer interpretations on the fracturing capacity of AN and expand on the idea that to discover is to suffer.

"We're Not Those People"

In addition to the shock and heart ache of knowing that one's child is experiencing a life-threatening, medical emergency, parents also found themselves questioning how they let things go on for so long. A feeling that parents were failures emerged during multiple interviews. Parents doubted their perceptions of the family they thought they had and found themselves questioning their parenting practices. In a powerful exchange, one mother stated:

> The part where you get to the point where you realize like, you missed, like you just totally missed this like, how could you miss this for your child?… I would think all the time like "we're not those people. We're not those people." We were all still together at the time and we were a functional family. We're professionals, we take care of our kids.

> We drive them places, we eat dinner together, obviously we do all other things you're supposed to do because I'd read all the books about what you're supposed to do right. I wanted to be good at this. I wanted us to have a happy family. So, to find that that is not what happened was really, really painful like to come to that realization. (Lynne)

This quotation speaks to not only the experience of coming to the realization that something was wrong and had been wrong for some time without one's awareness, but also communicated the uncertainty she had in herself as a parent. When parents who tried hard to create a balanced, safe, and supportive life for their children realize that, despite their best efforts, their children are in serious danger, they cannot help but take a look back on life as they knew it. Further, a sense of disappointment is illustrated in this quote, and was discussed generally with all participants. The expectation that, if parents are together, supportive, encourage their children to be involved with extracurriculars, eat meals together, et cetera, then generally the family unit will remain stable, successful, and happy, was challenged.

The discovery also caused parents to question their competency and roles as mothers and fathers. After learning that one's child had been sick for many months, yet was flying under the radar of parent's awareness, a crippling sensation of guilt was experienced:

> What did I do wrong? I gave them all this love. I was so involved in their lives. They came home for lunch every day. I was there for them and stuff, so then you sort of go through all those things and, like, should I have done this? Should I have given them more independence… so I really took it as a judgment on myself… it was like a final report card for me, and I took it as my greatest failure. (Gillian)

Feeling like one had failed their child was heavy in the air during discussions with parents. This perception of failing your child fractures the belief of being a competent parent, leading to

skepticism of parenting practices. As one mother stated, "there was sort of a feeling of being a little bit robbed. I tried to do everything right and still got it so wrong" (Lynne). When AN presents itself, it challenges parents thoughts of their competencies. Further, after discovering one's child has AN, parents belittle themselves with thoughts of, "now I really have to pay attention because I was not doing my job before" (Lynne).

Anorexia nervosa becomes a force that puts thoughts of insecurity into parent's heads. It makes them question their effectiveness and causes them think they have failed as parents. Anorexia nervosa also causes parents to feel relational guilt (Doka & Aber, 2002), meaning the guilt resulting from a parent's belief that their own inability to be an effective parent contributed to the problem. Simply put, AN shatters the belief about oneself as a parent. Like a mirror breaking, what was once whole and complete, is transformed into a fractured surface, with sharp, jagged edges, literally causing danger to those around them. The person looking into the mirror no longer sees themselves as they did before it shattered – the lines of broken glass interfering with the mirror's reflection. The image and beliefs that parents once had in their abilities to parent and raise healthy children becomes shattered, with the mirror no longer allowing them to see themselves as competent. When considering this interpretation, the old superstition about breaking a mirror and bad luck comes to mind. This superstition has been traced back to ancient Roman times when it was believed that the reflection of the individual looking into a mirror was actually his or her soul (CBC, n.d.). Further, if this mirror broke, the soul would be trapped inside or damaged (CBC, n.d.). Taken together, the pieces of broken glass reflect a parent's shattered belief in themselves as competent parents and also into their views about how things work in the world.

Self-blame and criticism. In addition to uncertainty towards one's parenting practices and competencies, it seems that self-blame is not too far behind. While parents spoke, I heard on a deeper level tones of criticism and contempt. It was as if parents believed that by changing one thing in their parenting repertoire that things could have been different – maybe AN would never have reared its ugly head. The following is a stanza extracted from a book of poetry, titled *Failure: Poems* (2007, p. 19), describing how a grandmother caring for her granddaughter left to check the mail for a few moments, and when she returned, realized that her granddaughter had fallen into the pool and drowned: "The woman, who had lived most / of her life on the good side / of this moment, left to get mail, / heard a door open and ran / to find everything once luminous / and unyielding smashed." This poem describes how life can change tragic in an instant. Life is fleeting, described by Schultz (2007) as a "moment," things can happen so fast that they leave us reeling, wondering why and even how such a thing could have taken place. When such tragedies strike, they leave those in charge feeling like their hearts are being ripped out. Questioning themselves and their actions, these figures who are supposed to be in control and responsible are left desperate. The feeling that Schultz is describing in *Exquisite with Agony* is full of relatable, universal moments – moments that leave us questioning why we had to leave at that exact point in time, moments that make us blame ourselves for what came later. If only something could have been different, this whole situation could have been prevented. The self-blame and criticism following a tragedy is inescapable. This blame follows us and holds the unwavering ability to throw the harshest judgement unto ourselves. After such events, we yearn to escape the person who could have let this horrible thing happen - ourselves.

Putting parents in difficult situations. When trying to make sense of the period of time between when parents were certain something serious was happening and the time(s) services

were accessed, I was curious about how much time passed before the parents acted. *How can six months go by and no action be taken? Maybe parents truly do not know that anything serious is occurring. Maybe parents are too scared to act. How can parents not notice that their child lost 50 lbs?* In conversing with parents and trying to understand, it became clear that this discovery and coming to terms with reality that their child was seriously compromised was difficult, and made parents feel like villains. Many families used the term "confront" meaning a face-to-face meeting or the clashing of forces (Webster-Merriam, n.d.) to describe interactions with their child during the discovery process. Essentially, in parents' discovery experiences, there came a time when parents decided to face the situation head on and call attention to what was happening with/to their child. These interactions often took the shape of planned conversations, with the intent to end the secrecy and move on to the recognition/diagnosis stage.

The language chosen by parents alone alludes to feeling as though parents are on the opposite side as their child, having to go through a harrowing, intense conversation with their child, if they are to communicate what they need to. One mother described how she came to the heart-breaking decision to face her daughter out of fear and determination that something needed to be done, "You don't want to hurt your children's feelings and you don't want the confrontation with your children, so people don't act… it's easier just to bury your head in the sand" (Gillian). Parents understand that confronting their child is an emotionally daunting task, as it entails building up the courage to call attention to what they have been noticing (i.e., changes in mood, behaviour, eating, and weight) and also requires parents to decide and enforce that others will become involved and what action will be taken in response. Perhaps in the cases where prolonged periods of time pass from an outsider's perspective, parents are caught in the shame of failing their children, while also being fearful of the anticipated consequences that confrontation

will have on their relationship with their child. While recounting watching her daughter's body continually decrease in size, one mother shared her inner struggles of whether or not to address the issue of body weight and size, implying needing to have a sensitivity when addressing these types of conversations with others. She said, "I think it's hard to have that conversation, because as parents you're not supposed to focus on your child's weight, but sometimes you need to focus on your child's weight" (Joan).

During conversations with parents, I could not help to be surprised and moved at the severity of their experiences. The idea of parents being afraid to act due to the perceived consequences that would ensue made me think deeply. I had never considered this relational element prior, yet the more parents spoke of being wary to approach their children about what was happening, the more it made me reflect on situations I have pondered about for years. In the past, I have been a peripheral observer, noticing dynamics within families or partnerships that I deemed to be problematic. It is like the rest of the world can see that something is not right and needs to be changed or addressed, yet the individuals making up that unit are either oblivious to it or in denial, or maybe a third perspective – fearful to act, as the consequence might even be more harmful than the problem itself. As an outsider, it is easy to look in and want to demand change. *How can you not see this is a problem? No, everything is not alright.* It is easy to be judgmental, for we know nothing of that family's struggle.

Fracturing, or the state of being broken encapsulates the process of discovery at every stage of unfolding. Parents hope for healthy and happy children, not children in danger of an ED. Anorexia nervosa causes extreme damage in numerous ways that affects the child, parents, and family as a whole. Anorexia nervosa also has a fracturing, breaking, disruptive influence

over parents' beliefs about themselves. Finally, AN violates parents' expectations of life - fracturing hopes, dreams, and values.

Betrayal and Loss

Almost all of the parents interviewed described a close relationship with their children, marked by trust and open conversations prior to the development of the AN. As their children became sick, they described a change in their relationships. Many interactions were portrayed as "deceitful," describing how the once open relationship had been transformed into a secretive interaction style where honesty was no longer the expectation. When listening to these parents, the hurt in their voices was clear – they had felt lied to by their children. Whether children no longer confiding to their parents was considered a betrayal, or parents felt like the intentional holding back of the whole story was deception, the relationship felt tainted. As one mother said, "I couldn't imagine, like I mean, I spent, like we're close and I spend a lot of time with her. And I just couldn't, I just couldn't believe that could be possible… I knew she struggled. She has always been this kid who has shared every emotion" (Elizabeth). The idea that a parent and child could be so connected to each other, have shared passions, and spend great deals of time together appeared to make this a very hurtful experience for parents, especially mothers of daughters. Based upon the literature on AN and how this illness thrives in secrecy and gains momentum (Hamkins, 2005), it may not be the child's intentions to purposely lie to their parents, however, this filtering of information was felt strongly by parents.

In a sense, AN temporarily fractured the relationship between parents and children. As Hamkins, a psychiatrist, argued, AN isolates the afflicted individual in order to manipulate and brainwash, thus pulling that individual from family and friends (2005). As one mother shared:

> When I look back at it, that's probably what bothers me the most, it's kind of the deceit and the dishonesty… we knew something was wrong, and we would ask, and yet we would be getting told "no, no," but yet we knew there was… in our mind there was dishonesty… And I guess maybe coming up to that weekend… because I was going to be seeing her face-to-face – I was sort of anticipating that maybe I'd be able to have a breakthrough and maybe be able to talk through and maybe be able to talk it out with her and we could make some headway into what was happening and what was going on, and then when we just were hitting roadblocks all the time it was sort of that deflation again and that distrust again and the deceit. (Dawn)

Feeling lied to under normal circumstances is difficult to experience and is amplified for parents whose intuitions are alerting them that something is wrong, yet their child will not provide them with the information they seek. Dishonesty is defined by the Webster-Merriam Dictionary as the "lack of honesty or integrity: disposition to defraud or deceive" (n.d.). The tone lingering from this word's meaning leaves one feeling cheated – resentful of the person withholding information and apprehensive to trust that person in any future circumstances. A heaviness lingers when considering that parents feel deceived by a child experiencing a horrific mental illness with severe medical complications.

In addition to feeling betrayed, parents experienced grief for their lost relationship, once marked by a sense of honesty and closeness. Being hurt by the mistrust and change of relationship may be embarrassing for parents to admit, thus representing "disenfranchised grief," a sense of loss that is not socially sanctioned or acceptable to express outwards (Doka, 2002). While scheduling appointments and advocating and caring for their children, to name a few, parents are not given the space to express their authentic feelings, in this case, the pains of being

kept out of their child's life. Parents may fear that sharing these feelings might yield judgement, understandably leading these parents to remain quiet. Some parents may lose companions who once were their children as well. Not only have their child's appealing qualities been muted, parents also have to adjust to a harsher existence, without the appreciation or love they used to receive from their child.

"They Won't Let Me be a Mom"

In addition to the betrayal felt by parents, the discovery of AN also challenged parenting practices and disrupted the roles parents took in the care of their children. Though the discovery process and what happened next was a heterogeneous experience for all parents interviewed, there was an overall sense that parents had their control taken away from them when involving professionals. The feeling like one's control had been taken away amounted to the loss of mothership, according to one participant,

> There's nothing I can do. Like I can't control any of this and they won't let me be a mom… It's all up to them. You know, and they don't ask for your help and they don't ask for input. (Betty)

Parents felt pushed to the side, which was incredibly difficult given that for months leading up to the discovery and official diagnosis, they had been trying everything to help their child get back on their feet – even if they were not sure what exactly their child was experiencing.

A parent cares for their child even before the child is born, they nurture and foster a safe environment, and encourage their child to grow and explore. A parent nourishes their child with both food and love, oversees social and emotional engagement, and arranges for services to overlook health and developmental trajectory. For some parents, somewhere in this process, their child develops AN, and everything changes. Parents who once felt competent in their roles,

now are made to feel inept, no longer in touch with what their child needs. During the discovery, parents realize that they have missed something and are told of the grave, near-death danger their child is up against. Though a sense of relief washes over parents initially due to their child being in professionals care, they know they have been pushed out of the picture, or perhaps even more fitting, the picture itself has changed. This evidently causes parents to experience great loss of control over their child and feel like their parental responsibilities have been taken away, yet again creating a fracture in their belief of what it means to be a parent.

In addition to feeling stripped from one's parental duties, the sense of loss of control was shared. Parents living through the discovery experience have limited or no control over the process, left in a limbo-like location of uncertainty and darkness. Parents are forced to let go of expectations, as they soon learn that hoping for things such as recovery, treatment timelines, family involvement, trip planning, et cetera must be put to the side. "It's like adjusting your expectations, that is was just like this continual letting go" (Elizabeth).

While learning to let go and adjusting to their new normal, AN fractures the integrity of the family, gradually breaking it down into components. Components are parts, elements of a whole, or qualities that when put together make up a complex product (Merriam-Webster, n.d.). As families are fractured; the individuals making up that unit become distanced, taking on different characteristics, no longer fulfilling the responsibilities that were once expected. Anorexia nervosa also has the capacity to break the rules and break confidences. Anorexia nervosa disrupts the trust and intimacy that once marked a relationship, and it forces individuals to no longer be able to rely on others in whom they used to have faith. It forcefully drives parents into roles they never wished to have. It challenges and distorts an individual's sense of self – even if that belief and identity was firmly held previously. Anorexia nervosa has a

shiftiness, stealthy characteristic to it. This clandestine quality allows AN to create rupture in families, violating sacred relationships, norms, values, and traditions.

To Discover is to Suffer

"Suffering occurs when we want the world to be other than it is right now" (Donsky, 2015, p. 185). To discover is to learn, and suffering is inherently part of this. Discovery without suffering is superficial; it is not complete. Parents of children with AN, or other life threatening or chronic illnesses, share a unique closeness that results from enduring and suffering as they learn or realize what their child is experiencing and the trajectory or future hurdles they may experience. These groups have experienced pain that others will never fully understand, and the suffering experienced becomes part of their self-concept.

> *A key element in contemporary hermeneutic theory of experience* is that there is something unavoidably difficult, and transformative, in the act of becoming experienced in the ways of the world. This experience extends across the whole gamut of human life, from small, exhilarating interruptions of one's expectations… to traumatic experiences of mortality, impermanence, and illness… Hermeneutically understood, education is centered on a concept from the Humanist tradition: *Bildung*, a German term meaning "self-formation." It is a process of *becoming someone*, a process that is undergone, endured, or "suffered" in the act of coming to know about oneself and the world. (Jardine, McCaffrey, & Gilham, 2015, p. 3, italics in original)

The term bildung, is fitting to conceptualize parents of children with AN. These people are transformed into new identities, identities in which suffering needed to be endured, in order for them to realize the magnitude of the reality they were facing. Parents become someone else throughout the process of discovery – perhaps not in the sense that their identities completely

disappear, and they must re-build a new persona from scratch, but different in that priorities change, values shift, routines are modified, and time once deemed as precious and untouched by illness is lost. In this way, suffering can be pedagogical in character (Jardine et al., 2015). To suffer, or "to submit to or be forced to endure; to feel keenly" (Merriam-Webster, n.d.) is often a necessary and authentic part of learning. How else can we truly learn a lesson without feeling its effects or consequences? In this way, learning without feeling or enduring the pain associated is incomplete. As Jardine and colleagues (2015) wrote,

> This is an ancient idea from the Greek tragedies of Aeschylus (c. 525 BCE) – *pathei mathos*, or "learning through suffering." In our understandable rush to ameliorate suffering at every turn, and to consider every instance of it as an error to be avoided at all costs, we explore how the pedagogy that can come from suffering becomes obscured. (p. 3)

Consequently, when rushing to find solutions to our problems, we miss something vital to our learning. Rather than taking a moment to reflect on the pain, we have created urgency to fix our suffering, thereby losing part, if not all of the lesson and wisdom we could have absorbed from the situation. Jardine, Gilham, and McCaffrey's (2015) text, *On the Pedagogy of Suffering: Hermeneutic and Buddhist Meditations*, is powerfully convincing and related to discovery. Finding out that one's child has AN is learning, yet it becomes discovery once the pain that accompanies this realization is felt and acknowledged. Thus, the experience becomes fracturing when parents discover the life-threatening, severe, and ambiguous nature of AN, and the little (or no) control they possess over the situation.

> Suffering, like depth psychology and alchemy, offers a way of knowing, a way of seeing, a way with the unsaid of life. Suffering is a way to see by means of black. It seeks to

make darkness conscious, however disagreeable and unpopular. Suffering as pedagogical is a move in depth from the analytical mind to soul, a move against the current trajectory in education, the helping professions, and the historical stream of our culture… Suffering as a vital part of human life is a clear call to hermeneutics as a way to inquire and dwell in the mystery of life. (Fidyk, 2015, p. 106)

Chapter Six: Concealing and Revealing: Aletheia

Through conversations about discovery, it became clear that parents felt their children were slipping away. In the way parents spoke, it was like the person they once knew their child to be was no longer there, and instead a shell of their child remained, inhabited by someone they had never met. The phrase *a shadow of your former self*, seems relevant to this interpretation, signifying "someone or something that is not as strong, powerful, or useful as it once was" (Cambridge Dictionary, n.d.). Reflecting on this phrase and what it refers to, I wish I had asked the parents I spoke to of their thoughts regarding this idea. I think it would have meant something to them. Based on my perspective and position in conversations, parents described their children's energy and auras as not being the same as what they once were, almost as if the fullness of who their child was had been muted. Parents noticed that as AN crept in, their child moved out. In addition to the fracturing capacity of AN, discovery is also a time that parents recognize they have lost their child to something strong and beyond their understanding. In this chapter, I offer interpretations of the Ancient Greek term *aletheia*, children being lost and found, how AN finds a way of controlling the child, and how children conceal AN for a time until they cannot.

Lost and Found: Aletheia

Being lost, not knowing where one is or the inability to find one's way is the experience of parents with a child with AN. As months lead up to the eventual discovery or confirmation that one's child has AN, parents are fearful and unsure of why their child is no longer them self. This experience relates closely to the Greek term, *aletheia*, describing some act of uncovering pieces of understanding, at the expense of closing others (Moules, 2002). As Moules (2015) articulated:

> Aletheia is a word that is about unconcealment. The word is the opposite of Lethal (dead) – aletheia then means to enliven. It is also connected to the mythical River of Lethe in Hades: the River of Forgetfulness – a river that, if crossed, erased memory. Aletheia is the antithesis of this: it is about remembering. In its unconcealment, enlivening, and remembering, aletheia brings home what may have been lost, forgotten, deadened, or concealed in our "simply getting by". (pp.1- 2)

When considered in context of the topic, AN becomes enlivened. As AN grows in strength and determination, it begins to take shape as a dark, greedy force, wanting parents to forget the exuberance with which their child once lived their life. Anorexia nervosa works to conceal, to make people forget the good times, when life was easier.

As I reflect on this Ancient Greek word, integral to hermeneutics, I am struck by its complexity, yet universality. Every aspect of life is marked by aletheia – as something is revealed, another is concealed. I remember when I was 16 years old and learning to drive. I used to have nightmares of putting the car into reverse when I actually wanted to go forward, inevitably crashing into all sorts of things. While learning and practicing my maneuvers, my dad would always say to me, "Emily, one day, after you have been driving for a while, you will think back to when you were first learning to drive, and you will be unable to pinpoint the exact moment you went from beginner to experienced. You will forget what it felt like to be nervous." Whenever he said this, I never believed him. I could not fathom a time when I would be feeling comfortable behind the wheel, yet of course, as always, he was right. Six months later, cruising by myself down the highway or making left turns through busy intersections, I had already forgotten how nervous I used to feel. Fears of incompetence were replaced by excitement for road trips and driving with the windows down during the summer months. Now that I reflect on

my experience as a driver, I can recall a myriad of other instances in my life that have also been marked by aletheia – in this way, aletheia is universal. When bringing this up with my dad, he profoundly said, "That's what learning is: a process that brings you step by step forward until you separate from the time of not knowing" (M. Williams, personal communication, January 10, 2019).

As I continued to reflect on the idea that everything seems to be touched by aletheia, another example presented itself to me. This came in the form of a published text about Maslow's Hierarchy of Needs, in which the author made a personal disclosure. Cook (2015) provided an overview of Maslow's Pyramid, reminding readers that through Maslow's eyes, humans have certain needs, and may progress through needs including: physiology, safety, belonging, esteem, and self-actualization. Cook shared that for someone like himself, who manages bi-polar disorder, on some days he can feel supreme and self-actualized, while other days he experiences lows so excruciating that he thinks of himself as not worthy of living. While providing context for his experiences, his account struck me as an exemplar of aletheia, not too different from how someone with AN might feel. Not only can someone progress and regress through the hierarchy, but as they do, they lose the feelings they once had in their previous state, while gaining a different perspective from the level of the pyramid in which they currently are situated. In other words, no one and nothing is static, to believe that we have knowledge or experience that will remain the same forever is a fallacy. Cook (2015) elaborated further on the idea that his mental illness could not and would not remain hidden, again illustrating the enlivening and remembering of aletheia:

> My issues would not remain hidden. Like some beast they tore through me until they reached the surface and were staring out my eyes. I hope my friends knew it wasn't me,

> not the *real me*, but I wasn't in control. Maybe I was, but if I was, it was the darkest corner of my being. (p. 203, italics in original)

Just as suffering and living with ambiguity is a condition of being human, so too is aletheia. Perhaps aletheia has something to teach us about discovery. Perhaps it serves as a reminder of our impermanence and ignorance.

Relating back to the experiences of parents when discovering their child has AN, the particulars of a topic are both exposed and hidden at the same time, meaning that as parents begin to recognize or understand what is happening in their child's world, other integral elements of the situation are teared from their grasp.

> You're just trying to explain the change, and at that point in time, it's up in the air, I guess. You've got a lot of things that you're trying to discern or connect the symptoms with, but there's nothing clear about it. No clear rationale, reasons. The only thing that's tangible is the behaviour. They're not eating, and the mood and her affect – you know, her personality or persona. Those are tangible evidence that something's not quite right, but why, what's causing that? (Hope)

While pursuing the truth, parents are always one step behind, never able to capture the whole essence of what is occurring. During the process of discovery, as parents begin to realize something is not right, they lose sight of their child and they can no longer effectively communicate. Their child seems unfamiliar. While struggling to see and make contact with their child, AN begins to dictate these interactions and relationships once marked by trust and warmth.

Just as the elements of this topic hide themselves from view, or reveal only a glimpse of what is happening, so too does the work of hermeneutics. Hermeneutics finds its place in liminal

spaces, just as Hermes was the god that could cross borders and live in liminality. Being situated at a sensory threshold or in a place that is barely perceptible (Merriam-Webster, n.d.), hermeneutics offers parallels to parents being caught in this in-between state, being neither here nor there, seeing parts of the situation but not the whole. Hermeneutic work:

> lies in its ability to hold tension, to be "not quite this and not quite that," in recognizing that with every opening, there is a closing of something else, in knowing that openings are invitations and portals to understanding, not dark rabbit holes where the topic disappears. (Moules et al., 2015, p. 179)

Is it possible to root our understanding of discovery in the *openings and portals to understanding*, as stated by Moules and colleagues (2015)? When parents are invited into their child's experience what can they see? When the information they crave is suddenly made available to them, what do they lose at the expense of understanding? Perhaps one thing that is concealed as other elements are revealed are parts of parents themselves. Anorexia nervosa hides parents, as the endured pain of discovery clouds their minds and relationships. As Cohen and Bai (2015) wrote, "The person's upset is so powerful it cloaks the individual like a dense fog and makes him invisible" (p. 54). As parents are fighting to find a glimpse of their how their child once was, they too are being screened or sequestered from view. A parent's pain has such an effect on the situation that their capacity to see the situation clearly (or as much as this is possible) is compromised (Cohen & Bai, 2015).

Anorexia nervosa aims to stay concealed (Hamkins, 2005), gaining power at a steady rate. Much like an identity thief, AN steals an individual's life. Deemed criminal, thieves steal personal information, hack into private accounts, and defraud others - the same violations occur when AN develops. Individuals have spoken about cancer as an identity thief as well,

subsuming the personal and professional lives of those that unwillingly host it (Fiedler, 2011). While hiding deep within a child, AN's power grows, hiding the child from their parents, and hiding its own strength, intimidation, and influence from everyone else besides the child. While AN grows in silence, it pulls the child further away from the things and people they love and isolates the child to live in a dark place, silencing the child when they wish to scream out for help.

Related to the interpretation of being lost, Doka and Aber (2002) discussed the concept of psychosocial loss and grief, and in an introduction to their chapter described a scene from the 1956 horror movie, *Invasion of the Body Snatchers*:

> Unknown entities, for unknown reasons, seize the bodies of unsuspecting victims. These victims continue to lead seemingly normal lives. The parasitic consciousness now inhabiting the bodies gives only subtle clues to this new existence, one that is perceived only by those closest. The viewer is relieved when the film ends. The invasion is, after all, only a celluloid fantasy. (Doka & Aber, p. 217)

Although a fantasy for audiences, this is reality for parents with children experiencing AN. Though a parent's child has not died, the person they once knew is no longer available to them, representing a form of psychosocial loss and grief. While observing their child change into someone foreign, parents experience a profound sense of loss, not having any control of the situation.

Another concept, psychosocial death, where the "psychological essence, individual personality, or self is perceived as dead, though the person remains alive" (Doka & Aber, 2002, p. 219) seems relevant. This concept can be applied to many circumstances and has been especially linked to situations where individuals acquired chronic brain syndromes. Although

the circumstances are not quite the same as when family members die as a result of diseases of the brain, the discovery of AN brings about personal changes that have environmental impacts – in part due to physiological consequences of prolonged starvation on the brain. Though not taken by death, parents grieve the loss of a child's spirit, uniqueness, and familiarity.

> The concern with things which are not understood, the attempt to grasp the unpredictable character of the spiritual and mental life of human beings, is the task of the art of understanding which we call hermeneutics. (Gadamer, 1996, p. 165)

Parents attempt to understand as much of the situation as possible, which inevitably causes them pain when total comprehension is not feasible. Adding another layer of complexity to this situation is the ambiguity also involved in being witness to one's child changing, yet not having the words or comprehension of the reason.

Ambiguous Loss

> From a psychoanalytic perspective, ambiguous loss is indeed an uncanny situation of traumatic anxiety produced by a combination of the known and unknown (physically present but psychologically absent, or vice versa). The intellectual and relational uncertainty of living with someone both here and not here produces a terrible anxiety or bizarre human experience… In such cases, life is altered dramatically for the spouse, children, and the family as a whole. And no one sends a sympathy card or sits shivah for this. Instead, there is a lonely and oft misunderstood mourning with an indefinite beginning and indefinite end. (Boss, 2006, p. 5)

Boss' work on ambiguous loss has been influential in its application to numerous contexts. In such situations where parents face the unknown, yet still see their child sitting before them, it threatens the reality once known and trusted. How is it possible to lose a part of one's child?

What is a parent to do when the characteristics that once made their child their child have disappeared? In the absence of a missing person's report, how can the lost aspects of a child be found? Or better even, how do parents make sense of this?

As parents struggle with the parts that are missing and those that appear to still be intact, aletheia is in full effect. Greek for "truth," aletheia is also translated into "remembering" (Online Etymological Dictionary, n.d.). Perhaps the pain comes from the memory of how things used to be. Ambiguity may be amplified due to parent's understandings of how their child has changed and what they are experiencing, but also remembering how far that child has fallen into illness and the power of AN. To remember how different one's child was just a short time ago may make one want to forget how ill they are now.

Power Struggle

"There's just so much you just don't know, the eating disorder is just finding a way to get in every time when nobody is watching" (Elizabeth). The sense that a power struggle was always under the surface at the time(s) of discovery emerged during conversations with parents. Parents of children with AN come to understand that AN is a powerful force that attempts to take over their children when no one is guarding against it. As one mother explained:

> It's like she's in a big cage with this huge and ferocious animal, and my daughter's a prey, and all this animal wants to do is kill her, but before it kills her it's going to play and toy around with her, and it's going to make her suffer, and it's going to make her scared, and it's going to tell her things to make her quite submissive, so that, again, it's easy. She's an easy prey. (Hope)

Numerous stories of children reaching out for help in the early stages of the illness were shared, leading one to believe that before AN conceals the child from others, the child has the

power and authority over it to reach out for help and express something is not right. Many children approached their parents with concerns of hair loss, anxiety over physical appearance, weight loss, and persistently feeling cold. Though parents stopped and listened to their children, none took these disclosures as cries for help. As conversations meant to communicate extreme distress went unnoticed, children fell deeper into the throws of AN, undergoing transformations both physically and psychologically at the hands of the illness. With each day, AN thoughts and behaviours become more severe, silencing children from speaking out.

Anorexia nervosa dominates. Adding to the complexity, for a time, AN conceals the child from the world around them, isolating the person in order to infiltrate their mind. During such periods, it may seem like children conceal AN from others, adamantly insisting nothing is wrong. As Hamkins (2005) suggested, AN thoughts come to dominate and proliferate a person's thinking and behaviours, essentially leading them to lose touch with their values, identity, and relationships. Thus, with this interpretation, it is not surprising to hear that children deny that anything is wrong. One mother shared, "we talked to her about [it] and she got very angry and defensive" (Elizabeth). As parents' suspicions mount, and they ready themselves to have a fierce confrontation, the child responds to the challenge with anger and defensiveness – *nothing is wrong*. Though parents may not pursue further dialogue after being shut out, their intuitions and inner alarm bells continue to sound.

Passage of time – Un-concealment begins. Some weeks or months later, as tensions mounted within the family unit, and parents began re-approaching their children regarding the source for their changing moods and behaviours, children were too far gone and pulled into the AN darkness to resist help to be pulled out. "We had to fight the beast. Let that eating disorder know, because my daughter can't fight for herself right now… It likes to hide in the deepest

darkest corner, it does not like the light to shine on it" (Taylor). In this sense, children with AN are stuck in figurative quicksand – not able to drown, but not able to move either. The child is stuck, lodged in the quicksand – a mix of sand, clay, salt, and water, that from afar appears solid. Perhaps briefly reviewing the grossly simplified physics behind this phenomenon may provide insight into the stuck-ness children and parents feel. Due to the reduced friction between sand particles in quicksand, objects falling into it begin to sink, yet they do not become fully covered (or drown; Hammond, 2016). As the sand gradually begins mixing with the water, the buoyancy of the mixture increases, causing the object to float back to the top (Hammond, 2016). So, though one cannot drown in quicksand, it does yield one stuck, relying on something external for help. A researcher from the University of Amsterdam re-created quicksand in the lab and found that just to release one foot, a force of 100,000 newtons – the equivalent of the force to lift a medium-sized car, was required (Hammond, 2016), providing a clear demonstration of just how stuck one can get, and the near impossibility of becoming un-stuck without assistance.

When parents re-approached, taking up arms against the AN, children did not object and had no more energy left to continue concealment:

> I just held her for a long time and she cried herself to sleep that night. But I don't think it was tears that she was mad at us. Looking back at it, I think it was tears of "I don't have to hide anymore." So, everything was out in the open. (Taylor)

Similarly, another parent shared that by the time his daughter was very ill, there seemed to no longer be any resistance when his wife and him sought treatment for her:

> There was no resistance on her part. There was no "F you, I'm going to do what I want to do"… Bottom line is, when her mom eventually told her she's not going back to school, she was relieved. There was a sense of relief… What we found is that most of these kids

> want somebody to make a decision for them because their bran can't function to make a decision for themselves. (Pablo)

Previous literature on disclosure has found that many individuals with EDs feel they can no longer hide from others, feeling "too far gone" to continue to conceal their behaviours (Williams et al., 2018). This appears to be confirmed, in the sense that after months of prolonged pain due to AN, children no longer resist their parents' efforts of caring for them and seem relieved that someone has taken notice of what has been happening. Thus, just as AN is concealed, it is also revealed.

Horizons

As we develop, interact with others and our surroundings, our horizons of understanding change. As experience is gained, the world is viewed differently. With the gift of being able to see further, we lose sight of that occurring behind us. As we live, experience, and learn, we are in-tune with different foci, leaving our connection to the past a little weaker than it was before. As our fore-structures and biases come together, horizons open and become larger, allowing us to see, reflect, and consider concepts that were not available to us before. As Gadamer clarified:

> We define the concept of "situation" by saying that it represents a standpoint that limits the possibility of vision. Hence essential to the concept of situation is the concept of "horizon". The horizon is the range of vision that includes everything that can be seen from a particular vantage point. (1960/2013, p. 313)

In this way, horizons are inherently connected to aletheia and the expansion of understanding, at the expense of concealing something else. To acquire a horizon means to be able to look at something beyond what is close and easily accessible, not with the purpose of looking away from it, but rather to see it better, with the larger picture contextualized (Gadamer, 1960/2013). Some

biases or pre-determined ideas about a particular must be silenced, or concealed, in order to learn more wholly about that particular. Hence, discovery is a delicate time that allows parents to come to the realization of what their child is going through, yet all the while recognizing that they will never completely understand what caused AN, how their actions may have contributed to the development or maintenance, or what the future may hold. Just as children with AN are held captive, so too are their parents when they discover.

Chapter Seven: When Something Needs to be Carried: The Unspeakable Nature of Anorexia Nervosa

A metaphor is a "figure of speech in which a word or phrase literally denoting one kind of object or idea is used in place of another to suggest a likeness or analogy between them" (Merriam-Webster, n.d.). The metaphors used to describe discovering that one's child had AN were overwhelming - - overwhelming in the sense that every parent used this tactic at explaining the experience, and also overwhelming because the use of metaphors conveyed that this literary device was necessary for parents who could not put into words the raw emotions they lived through. Something about describing their discovery using an alternative description may have given them space that was required without being enveloped back into that dark time. Alternatively, metaphors may have been used to create a bridge of understanding between myself and them as a group – a way for an outsider to connect to what it was truly like to find out that one's child had AN. My purpose in this chapter is twofold: the first will be to highlight the use of metaphor and its way of carrying the experience of parents' discoveries, and second, I will demonstrate the unspeakable and even unthinkable nature of AN and the strategies parents used to manage coming to terms with the discovery.

Metaphors as Carriers

"As parents, you're in this boat, it's rocking, and you don't quite know how to stabilize it" (Ritch). "It was this crushing feeling of just like. This isn't like a broken arm, like this. I think we're really in it" (Elizabeth). "It's almost like the frog in a boiling water kind of scenario, where you're in there, the heat gets turned up a little bit, and then all of a sudden you're here and you don't even know it" (Brian). "I think as of myself as a salmon going against the flow of

things" (Taylor). The beauty of metaphor is that no explanation is needed. These quotes are demonstrations of the visceral meanings and experiences shared through language.

Metaphors worked to carry parents' meanings, helping them to find words that described their experiences. The use of metaphors acted as both barriers and bridges. Perhaps delivering metaphors was easier for parents, as they put one at a distance from the experience actually being described. They create barriers and block the raw, overpowering emotions once felt and act as a buffer when relaying one's experience. Sharing a phrase or word may be a way to convey the unspeakable pain, helplessness, and shock parents felt when they learned their child was experiencing AN. The use of metaphors may have also been used for impression management, giving parents just enough space to describe their experiences to an outsider – while protecting themselves from reliving that time in their lives. Alternatively, metaphors were shared as bridges, offered to me with the hopes that I would understand the intended meaning. Metaphors in this sense acted as a transition, a place and time to connect and learn about an experience that personally, I may never know. In all cases of metaphors used, parents took an abstract, ambiguous concept and related it to something of a concrete nature. By showing me, and not telling me explicitly what it was like to discover their child had AN, a powerful perception of understanding washed over me, and I was able to connect with these parents and create a shared sense of the experience.

When talking about difficult topics, "broad, universal concepts and images and ideas are always needed in the act of articulating one's experience. We always run the risk of using words that can be understood differently than we meant" (Jardine, 2015, p. 86). Metaphors or universal concepts that do not require explanation carry our intentions when we do not have the words that will bridge the distance of understanding. The feeling of discovering one's child is in the throes

of AN has no literary equivalent, leaving us with devices such as metaphors to do the work of explaining. Hermeneutic research on cancer and its impossibly horrible nature reveals similarities to this topic. As Jardine stated:

> Cancer will never leave our consciousness. There are myriad ways of experiencing it, articulating it, investigating it, naming it, and these have cascaded down to us over time, admixed, sometimes battling each other, sometimes quelled, finally, in the soft presence of death. We can never say once and for all what needs to be said. (2015, p. 84)

As one psychotherapist explained, "meanings can be *milked* or *mined* for their gems. Or they can become *mired* in a swamp of endless significations" (Finlay, 2015, p. 338, italics in original). This quotation points to the potential advantages and dangers of using metaphor to convey meaning. On one hand, metaphors can carry a meaning and those in conversation to a new place of understanding, acting as a powerful tool of connection to a sacred and intimate experience. Conversely, the intended meaning or emphasis may be lost in translation, leading those in conversation to a muddied perception of what is being described. In the case of this research and parent's experiences, their metaphors served as a tool of connection, in their efforts to explore their past, while making sure I was a partner in their recollections. Just as language is ambiguous and allusive, so too is the experience of discovering one's child has AN.

"Part of Me Not Ready to Go There"

Just as how parents struggled to put into words their experiences of discovery, it became clear that they also struggled to think about what could have been happening with their children. When something is unthinkable, it is unable to be grasped by the mind, it is impossible to imagine or believe (Merriam-Webster, n.d.). Whether this was intentional or not, when parents

noticed changes in their child's moods, patterns, behaviours, and relationships, there was an unthinkability that something could be seriously wrong. One mother explained,

> You don't really believe it… Oh it's just a phase. Oh it's just this, oh she's trying to eat better. So there's this justification you sort of buy into what they're telling you because you don't sort of want to see what's there. (Lynne)

Like this mother, parents searched for alternative, less serious rationales for why their child was somehow different. While deep in reflection, another mother shared,

> I remember camping with her and stuff, and she was like "Nope, I'll just not have that extra serving," and "No, I'm good for dessert," but she was eating healthy, and she was losing a little bit of weight. She was looking good. She seemed to be quite confident… I knew she was losing some weight, but the way we were seeing it was she was making good choices… and she was working out a little bit, so I think in our heads it was "there's some maturity." She's starting to pay a little bit more attention to her presentation. (Joan)

Whether attributing weight loss and irritability to adolescent development/hormones, transitioning to new schools, or joining sports teams, the parents that I spoke to did not allow themselves to go straight into thinking it was anything serious. When considering this situation, the concept of self-preservation, referring to one's instincts to maintain their existence, or to preserve one's self from harm (Merriam-Webster, n.d.) comes to mind. This process essentially protects individuals from harm or destruction and relates to the weeks and months leading up to the discovery that one's child is seriously ill. Individuals in general fear the unknown, they are afraid of uncertainty. By not looking for reasons that indicate an underlying problem, there will not be a problem to manage or solve. Perhaps, by delaying the discovery by a few months, this

gives parents more time of normalcy, where no shocking discovery has been unleashed on the family and everything they are involved with.

> I feel like I wasn't ready to hear that it could be something or even entertained the idea that is could be something really worrisome… You just don't want to think that your kid can be that sick… So I would try and, it's almost like I was pleading with her not to be heard or something. I trying to minimize that I think because it was so scary to me. (Elizabeth)

This quotation represents temporary denial that served to protect parents. Wanting to have more time where nothing was wrong was an unspoken sentiment, but undeniably felt. Based on conversations had, it makes one consider the mindset of, *if we do not acknowledge it, then nothing can be confirmed, and our lives will remain the same*. Parents admitted that denial and minimizations of their children's symptoms and changes in behaviour occurred as a way of protecting themselves. If the underlying issue is not acknowledged and confronted, then the status quo of the family unit remains untouched. "It lurks in the back of your mind for a while. And you ignore it. Or you try and explain it away in your brain" (Elizabeth). It was easier to believe that a child was struggling because of normal developmental milestones than to know the truth. To be ignorant towards the situation preserves ordinary life – until the discovery has been made, life goes on untouched.

Similar to the stories my participants shared, a parent of an adolescent with AN shared her experience in a biography. She spoke about the challenges inherent in her daughter's and family's journey battling AN, and of most relevance to the discovery process, she provided a visceral depiction of the moments when all of her suspicions and concerns came together. She too was unable to respond initially, somehow held captive in the moments of the in between:

> As the other parents in the bleachers clapped and cheered, Jamie [husband] and I sat alone. It was as if someone had turned off the sound. When I dared look at my husband, I saw my own terror mirrored in his eyes. We didn't say a word; we didn't have to. The next morning I called Dr. Beth's office and took the first appointment offered – for the end of June, three weeks away. If I'd said it was an emergency, we could have gotten in earlier. But I felt oddly fatalistic about the appointment. We would take the time they gave us, and until then, I told myself, I would stop worrying about it. Stop thinking about it. I knew, then, on some level; but I still didn't want to know. I was engaged in the magical thinking of denial… Over the next three weeks, Jamie and I behaved like travelers stranded on a small and isolated island. We knew the big ship would come, and that once it did, everything would be different. We were scared of the change that was approaching and also anxious for it. (Brown, 2010, p. 23)

Alone on a deserted island, surrounded by water, helpless against the elements, just waiting for something, anything to happen – this is the experience of parents discovering their child has AN. Knowing yet not knowing, understanding the situation but not willing or ready to face it, a parents' journey with their child and the AN feels nearly impossible to ready oneself for. Perhaps these are the reasons parents watch and wait, feel like hopeless outsiders, and do not act immediately because knowing once they do act, there is no turning back.

Eloquently written from the perspective of professionals in educational psychology and philosophy, Cohen and Bai (2015) wrote:

> Clients who come to us in a state of suffering, in fact, are suffering because they are caught between feelings and numbness. Their attempts to alleviate the pain are not working, and they are not able to fully feel the emotions that are affecting them. If they

> could, they would be able to complete the process that is lodged and immobilized within their psyche-soma. (p. 57)

In other words, when parents know something is wrong but cannot act or confirm it, they wait. They are caught in the in-between. They are confined in the ambiguity of their lives and the situation, the ambiguity of feeling pain and being numb. Finding themselves in a position of unthinkability, not ready to let themselves "go there," feeling stuck, and isolated, parents struggle. As Gadamer noted, "the true locus of hermeneutics is this in-between" (1960/2013, p. 306).

Chapter Eight: Coming into Focus

When I began this research, I was looking for answers to some big questions. I wondered why some parents took fast action in helping their children with AN, while others seemed complacent or hesitant to recognize or admit that anything worrisome was happening. I wondered what parents were thinking as they watched their child turn into someone they had not previously known. My curiosity then grew to wondering what it was like to discover and how this discovery took shape for parents of children with AN. In this quest for answers, I have learned that it is a lot more complicated than I had ever imagined. My understanding of the disorder has not only changed, but so too has my appreciation for parenting. Raising an individual, from infancy to adulthood is complex, especially when adversity is involved. I learned that parenting a child with AN is also a practice in learning to balance other family members, and realizing who you are as a parent, partner, and as a person. Parenting a child with AN is an exercise in caring for yourself when you feel this time does not exist, and it is being strong for your family and your child when feeling uncertain about the future. I have learned that when parents are faced with the realization that their child is in danger, sometimes, they are paralyzed with fear - - fear so great that it disturbs them, disrupts what they knew to be true about their child, their parenting, and their future. Whereas, for other parents, this fear does not work to paralyze, rather, it serves to propel them forward into action, into fighting for their child's wellness, treatment, and, recovery. For these parents, learning of their child's situation lead them on an expedition to save their child, often from the unknown, and to reclaim their child, who's essence had been taken over by something else.

Throughout my learning, I came across a passage about hermeneutics that resonated with me and elevated my thinking:

> …Hermeneutics lingers about the in-breath –" I was surprised at the moment… where something hits us and wakes us up out of our melancholia over the wearying sameness of things. It is where our living can become spacious and open and full of possibility again, and we no longer feel locked into the often-panicky confines and immediacies of our circumstances. (Jardine, 2015, p. 88)

This quotation illustrates the power of hermeneutics, the *so what*? Hermeneutics has a force to it, much like the power AN has over families and particularly parents discovering what their child is experiencing. Hermeneutics pushes us to learn more, to see more about the situation, all the while never claiming that every single thing about that topic or phenomenon be known. In this way, hermeneutics is alive. As the quotation implies, it (hermeneutics) lingers in the in-breath, it is fluid, nonstationary. Similarly, AN could be described in this way. In an instant, things can be different than seconds before. As I think deeply about the impact that AN has on parents and also consider the quotation above, it dawns on me that these concepts are related to life, a living, evolving, network, something that continues even when no one is paying attention. Whether it is starving to death or breath being the life source of human beings, there is something about these concepts that relates to survival and evolution. Akin to how we must continue to breathe to stay alive, discovery is not a one-time realization or event, discovery is a cycle, a process of continuation. Discovery can start as something small or big, a nagging feeling that something is not quite right or a shock that slaps you across the face, leading to a sudden realization that things are not as they seemed. Regardless of the initial impact, discovery continues, taking different twists and turns, and eventually transitions into something else. In this chapter, I will revisit the findings that I presented in the last chapters, with the intention to integrate these back to the overarching research question: *How might we understand the*

experiences of parents who have discovered they have a child living with AN? My findings do not stand separately, in fact, when incorporated together, they inform us of what it means, how it feels, and what it is like to discover one's child has AN.

Revisiting Discovery

After retrospection, further reading, writing, and provocative discussions with my peers and supervisory committee, I have come to understand that discovering one's child has AN is a constant search for meaning. Parents look for answers, they wish to better understand how their child came to develop AN, what AN actually is, and their child's and family's future prognosis. While, at the same time, parents also search within themselves as they try coming to terms with being a parent of a child with AN, what they may have done to cause it, sometimes struggling with adjusting to their new life routines and responsibilities. In this way, discovery is similar to hermeneutic interpretation:

> We will take interpretation as referring to what occurs when a really or apparently unfamiliar meaning is made intelligible… Hermeneutic theory concerns itself with just this process of interpretation. This seems unimportant enough if interpretation were taken to be merely a tiny fraction of human experience. It assumes universal relevance, however, as soon as we become aware that all human behaviour is based on making sense of things, even if only unconsciously; and ultimately this is the best evidence for the universal claim of hermeneutics. (Grondin, 1994, pp. 18-19)

Much like the quotation above, searching for meaning among parents of children with AN is universal. Just as how one may crawl into themselves to reflect after they have been given a life altering diagnosis, to be a parent of a child with AN is life-changing, requiring a period to digest the information that has just been learned. To discover, is to make sense of something. Even

while consciously not being able to understand, parents reported sensing something was not as it should be, long before they were able to consciously pin point what the issue was. In this way, discovery or interpretation does not require outward expressions or descriptions to make it legitimate, rather, discovery starts to occur when something unfamiliar begins to come into focus.

Parents of children with AN are changed by the discovery. They cannot revert back to their life and routines as they were before. Discovery brings parents to a place where the truth is seen clearly and sharply. Once parents see something for what it is for the first or 100th time, it can no longer be ignored. When AN is discovered, parents are forced forward in planning action items and seeking information, while at the same time, also set back in how they feel about themselves. When a parent discovers their child has AN, their identity as a parent shifts. After discovery, parents become caregivers, focused on specific health related tasks. As caregivers, responsibilities are elevated, and an urgency for providing caring tasks emerges. Though responsible for nurturing and supporting their child before the discovery, a parent's caregiver responsibilities now take up more mental effort, always keeping parents alert, diligent, and looking for the next opportunity to help. During discovery, a parent's role, and relationship with their child is altered, pushing and pulling a parent into terrain that is unknown.

Revisiting the Fracturing Capacity of AN

It seems that when discussing AN in general or being the parent of a child with AN, the concept of fracturing is ubiquitous. Defined as "existing or being everywhere at the same time; constantly encountered" (Merriam-Webster, n.d.), ubiquitous is a fitting descriptor. Stories of fracturing, the sense of frequent self-criticality and doubt, and considering oneself as a failure as a parent were present in every conversation. Whether parents berated themselves for not

intervening sooner, or expressed feeling betrayed by their child, it was evident that discovering their child had AN had the effect of shattering their identities. Before the development of AN, many parents reported feeling confident in their parenting, had strong, open relationships with their children, and believed they knew their children very well. Despite this once perceived strong attachment to their children, many parents felt their relationships weakening, and questioned the strength they once felt.

Even parents who considered themselves knowledgeable about mental illness and related issues felt AN's domineering and intimidating influence. One mother shared, "I am a social worker. I'm a counsellor… so I have worked with people with anorexia, but when it's in your home and in your face, the denial is so much stronger" (Donna). In this way, AN has a power to make people act or think in ways that they are not accustomed to. This seemed to be the case for this parent, who took a while to realize that her son was ill, even as an experienced counsellor who had worked with others with AN. Discovery has a fracturing capacity, as parents' identities as helpers and fixers are challenged.

Another important element to consider in this discussion of fracturing, is the pressures parents feel during the discovery. When feeling pressured to behave in a certain way, or to progress in an expected trajectory, people inevitably feel like they cannot measure up. A passage written by a psychotherapist and ED activist made me consider the pressures parents of a child with AN must consistently face:

> A client recently shared with me that she looked in the mirror at herself the other day and thought, "Meh". She wanted to talk about it because she wondered if that meant she wasn't recovered all the way yet because she didn't love her reflection in the mirror. It

> was a great example of what happens when we turn recovery into a new bar to reach or fall short of. (Cool, 2019, para 17)

Much like this client questioning herself and the progress she has made in treatment, parents of a child with AN also question themselves and their competencies. In this way, aletheia and the fracturing capacity of AN are connected. As a parent scrutinizes their ways of interaction and possible unawareness, aletheia is at work, making parents forget the many times they were supportive of their child, provided them with safe environment, and so on. When discovering one's child is ill and in danger, aletheia conceals parents' good qualities from view, making it difficult for them to recall their strengths as parents, leading them to become critical of themselves and what they must have done that lead to the development of AN. As time passes, and parents are able to comprehend more fully what is happening, they begin to create space for learning, for growth, and sometimes for self-compassion. The play between revealing and concealing presents as a natural movement, sometimes illuminating a parent's strengths, and other times obscuring a parent's belief in themselves.

Revisiting Concealing and Revealing: Aletheia

Parents told stories of some of the hardest times in their lives, stories of immense pain and fear. Although these accounts produced discomfort in their re-tellings, they were still expressed. There was a seriousness in the stories conveyed, as if parents needed their experiences to be heard. These parents came forward to be interviewed, not because they had been offered anything in return, but because they felt an urgency to share what they had been through, and somehow, hoped this sharing would make a difference. When asked why she volunteered to be interviewed, one mother said:

> I think it's… it's a pretty hush-hush thing and there's a lot of shame involved with it, especially from a parent's perspective… I think it's really important to have open discussion about it, and if people know my story or [daughter's] story or something, it gives them somewhere to turn for help. (Gillian)

Similarly, another mother shared:

> I guess the whole experience … the whole process as we went through it was such a learning thing, and we felt the whole time we just were at a loss... I just felt so… so helpless sometimes, so sometimes I'd think if there was maybe ways that we could help others so that if they are going through this process, maybe there's things that we could do to help others. (Dawn)

These accounts speak to the work of aletheia, of the interplay between revealing and concealing. It seems so much of the discovery and general knowledge of mental illness and AN specifically are shrouded in uncertainty, ignorance, and stigma. The parents that I spoke to all hoped that by sharing their experiences, that others discovering that their children have AN, will not feel so alone, helpless, or ashamed.

Throughout the course of discovery, parents described knowing something was wrong, but not being able to articulate it. As this uncertainty continued, periods of conviction that something was not right also emerged. It seemed that as parts of the situation came into focus, other elements become hazy, leading parents on a turbulent ride through the unknown. As parents came to understand more about AN and their child's encounter with it, parents held more power and resisted being pulled back into the dark, back into places of unknowing. I see this resistance as part of a power struggle, both against the AN and also against the anguish that parents felt throughout their discoveries. Looking backwards in time, all parents reported

wishing they had known or done something sooner. It is my guess that choosing to participate in this research was part of parents' reclamations of themselves as competent individuals, seeking out opportunities to do their parts in countering some of the pain they felt. These parents were (and probably still are) on a mission to reclaim something, no matter how small. Throughout interviews, I learnt that all of the parents that I spoke to had felt like they were pushed to the side, in the dark during many stages of their child's process of recognition, assessment, and treatment. These parents felt diminished by the health care system, feeling like they were along for the ride, with little control. In this way, parents felt robbed of their authority and confidence in their roles as parents. When it came time to share their experiences of discovery after the initial shock subsided, these parents were on a mission to reclaim their experiences, wishing that their words would reach others and help carry them through difficult times ahead. When asked to speak about his interest in participating, one father said:

> I think the number one reason is that it's good for me to talk about it, but number two, it would be really helpful for parents of kids to understand what we saw through our eyes, which I think can be quite different with what other people see. (Pablo)

In this way, by sharing their experiences, parents of children with AN were reclaiming part of the narrative that was taken from them during discovery, while also giving voice to how they actually experienced it. As I have written about in previous chapters, it is easy for others to judge a situation that they are not a part of and have an opinion about it. During interviews, it seemed important for parents that they were the ones who could decide how to tell their stories, as this was finally an experience on which they could be considered an expert.

Returning to the concept of revealing and concealing, AN is a sinister and convincing force that has the power to hide a parents' child from them and has the strength to trick parents

into thinking that something else was the cause of their child's weight loss, mood, or behaviour changes. Anorexia nervosa is a thief that takes people from their families, hiding them from view. At the same time, it seems that throughout the process of discovery and as parents received more information, their knowledge became a powerful agent against AN. As parents learn about the many factors that influence and maintain AN and treatment options, parents feel the need to give voice to what they went through, as this voice was often diminished and hushed. Like Gillian, Dawn, and Pablo, parents fight the oppressive forces of AN, and share their stories with urgency, as this is a necessary part of their journey.

Revisiting the Unspeakable Nature of Anorexia Nervosa

It dawned on me a few months after I completed the interviews that, although the parents who volunteered to share their experiences were courageous and genuine in their accounts, they were ultimately unable to fully express themselves when asked about their pain. The fact that during all 10 interviews, each parent offered a metaphor to describe part of their discovery experience was fascinating, and I have come to interpret this to mean that the loss of their child and their family during and after AN, were still too great to put into words. In this sense, the following quotation about inner dialogue and the search for meaning is moving:

> What is hermeneutically significant about language in this respect is the dimension of inner dialogue, the fact that what we say always means more than is actually expressed: "A meaning, an intention always goes above and beyond what is actually captured in language, in words that reach others. An insatiable yearning for the right word – that is what constitutes the genuine life and nature of language." (Grondin, 1994, p. 123, citing Grenzen der Sprache, p. 99)

Paradoxically, within a passage about language, the words "an insatiable yearning for the right word" linger in my mind. There is a parallel at play here, between longing for the right word, and desperately searching for the understanding and knowledge of what is happening to one's child with AN. Though AN manifests in obvious physical ways on the body, what parents seemed to struggle to put words to was what was happening to their child mentally, which ultimately was the content to which parents did not have access.

When I consider just how devasting AN is, I must look no further than to remember that AN thoughts are so powerful that they convince people to starve themselves. A force so strong is difficult to put into words and hard to even conceptualize. When something is so compelling that it can convince someone to stop eating, it is almost impossible to speak of. Parents of children with AN are frequently reminded of the danger their child was (and maybe still is) in. When loving someone so fiercely, the thought of an intangible power wishing for them to starve is unspeakable.

Revisiting the Title: Coming into Focus

Returning to the guiding question for this research, I think about the focus of a camera lens. The person behind the camera points their lens towards the subject to be captured. Initially, the subject appears out of focus, not clearly defined. Not until the camera is manually adjusted, does the subject come into focus, now clearly standing out. The subject is no longer fuzzy, the hard edges and vivid movement captured by the lens cannot be forgotten or ignored. This camera analogy helps me to understand how parents come to discover that their child has AN. Parents are aware of their child's presence, how much space they take up in the world, their routines, and their ways of interaction. However, being aware in this sense is not discovering. In every account I heard, parents were aware of their children, but not tuned in fully enough to

realize that their child was suffering and by what cause. It was not until their child was brought into sharp focus, through mounting signs and symptoms that something was not right, did parents finally understand.

To come into focus however is not to stay in focus. The focus that one's child comes into is fleeting. Parents have moments of clarity when they grasp what is happening, when they are able to pay particular attention to the specifics of the situation and their consequences. These moments of clarity are followed and/or intermixed by periods of uncertainty. It seems like this coming into and out of focus is a continual movement, that parents journey through in their experience of discovery. When a parent questions their competencies, behaviours, or habits, AN fractures a parent's identity and the way they believed themselves to be. Parents are pushed off tilt, they are challenged to find a way back to themselves. Aletheia, true to its translation and history, constantly is at work of revealing focus and clarity, while concealing other integral elements of understanding from a parent. Finally, to be in conversation with parents of a child with AN and hear them use metaphors to convey their experienced pain forces everyone involved to be acutely aware of what was/is at stake in the situation, to have been so close to losing one's child, yet to have been so far away and out of focus, to have felt helpless while the AN was taking hold. Moments of clarity and focus, moments of uncertainty and ambiguity - - this is how it feels to discover one's child has AN.

Chapter Nine: Changing Focus: Adjusting the Aperture

I consider this research to be a departure from traditional topics and ways of knowing. The majority of research on EDs has focused on etiology, models of maintenance, treatment clinical trials, and rates of recovery. Very few opportunities have been created for the study of what happens during the in-between or transition phases for both individuals with AN and their families. After attention has been placed on assessment, it is then transferred to discussing treatment options. The focus gets passed along from one area marked with importance to another, and discovery is skipped over entirely. With this research, I have created room for the study of events that have been deemed as less significant. Though deemed as less significant by researchers and clinicians choosing to focus their efforts elsewhere, I understand that this topic has grave importance for parents and families of youth with EDs, and also recognize discovery as being an area with significant portals for practice change. Equally, utilizing the method of hermeneutic inquiry to learn more about this experience lead me and parents down unexplored roads, uncovering realizations and "a-ha!" moments not expected. It is through these conversations and interpretations, that I believe the voices of parents of children with AN need to be heard and should be listened to, as they have important lessons to teach us.

Rigor and Integrity of Hermeneutic Inquiry

Hermeneutic interpretations are fluid, often changing directions and foci as the researcher continues to reflect, better understand the topic, reviews the literature, and consults with others. As Moules and colleagues (2015) explained, at the beginning of analysis, interpretations are comprised of particulars of the topic that catch our attention, surprise us, and call out to be better understood. These initial interpretations are then deconstructed and reconstructed based on continued reflection, reflexivity, reading relevant literature, writing, and re-writing. When

working in a group context, the researcher who completed interviews and interpretations is able to share their thoughts with others who then offer their insights, curiosities, and reflections on the interpretations. In my case, the "others" who I consulted with were eating and weight-related experts and authorities in hermeneutic inquiry, whom were able to evaluate my interpretations and their possible connections to the topic. When sharing my work with this group, the interpretations were elevated to a higher level. It was through this iterative process that my hermeneutic interpretations and writing acquired their rigour.

Further, as interpretations were constructed and deconstructed, fine-tuned, and revised, this constant process of back and forth and further reflection is what allows the product of a hermeneutic project to be capable of bringing about change. This approach to research listens for the particulars of a topic and does not accept that a topic is a certain way because of many repeated accounts or the same elements continuously appearing in the analysis. Instead, hermeneutic inquiry wishes to disrupt this narrow view of what makes some research have more authority than other research:

> Hermeneutic work, true to its phenomenological roots, encompasses a rich description of the phenomenon, but it must also complicate the description through highlighting exemplars, possible counter exemplars, by exposing the phenomenon to contextual material, and by engaging in deconstruction, so that we are not simply imprisoned by our interpretations in our own standpoint. (Moules et al., 2015, pp. 119-120)

Part of the power of hermeneutics is that it brings about new possibilities for improved practice. This integrative interpretive process allows us to disrupt the cycle of how practitioners and institutions are used to working and allows us to take up space in order to insert new

possibilities. In the following sections, I offer implications for clinical practice and their relevance to both counselling psychology and the mental health field in general.

Treatment and Psychoeducational Implications

The results of this study demonstrate that parents of children with AN desperately need additional information and support, especially in the early stages of their child's illness. As one mother light-heartedly suggested,

> It sounds dumb, but that would have helped is some sort of onboarding or some sort of like, the parents going to some sort of course for a day or some sort of "here's really what anorexia is." "Here's what it looks like." "Here's what refeeding is. She's starving for so long. She's going to need a gazillion calories a day, not what you guys are eating." You know what I mean? We had no coaching. (Elizabeth)

Similarly, another mother shared,

> What I found most difficult in the whole diagnosis piece was the lack of resources, the isolation, the lack of support for her, the lack of information, the lack of explanations, the frustration of trying to find resources to help her… having to take a great deal of ownership. (Hope)

Elizabeth and Hope were referring to needing a discrete period of time where parents are given all necessary information about the disorder, treatment options, and practical information regarding caring for their child while either waiting for services to commence or during the in-between stages where children are advised to stay at home. As such, psychoeducation formats, either individually or in small groups, would be helpful, as parents may feel better prepared, have a greater understanding of AN, and have a general expectation that life as they are used to is probably going to change. Though information groups already exist at ED programs such as the

"Orientation Group" that is offered by the Calgary Eating Disorder Program, these groups tend to focus on preparing the individual with the ED and their family for treatment (i.e., 1-hour overview of treatment options, expectations, whereby the youth/family is invited to consider pursing treatment with the program). Alternatively, what may be more important is a group focused on the parents/caregivers in which they are presented with information and are given ample time to ask questions. Further, if parents felt greater support throughout the early phases of their child's disorder, it may prove beneficial for treatment outcomes. Several parents interviewed shared that the first line of treatment recommended to them was family-based therapy (FBT; Lock, Le Grange, Agras, & Dare, 2001). The philosophy behind FBT for EDs asserts that children are embedded within the family and parents play a vital role in the supporting their children with recovery leading to improved treatment outcomes (Lock et al., 2001). Alarmingly however, these same parents reported not feeling prepared to engage in the treatment and encourage their children to consume more calories at home, as they were missing key information about AN, leaving them feeling incompetent. Thus, practitioners and overarching services may want to modify programming to ensure parents and other caregivers feel like they have the knowledge and skills to effectively support themselves and their children, before commencing into treatment. There are 168 hours in a week, and if the recommended treatment consists of one hour of intervention each week, parents must be supported in order to care for their child the remaining 167 hours.

Relatedly, when asked what parents wished they had known prior to discovering their child had AN, nearly all participants mentioned wishing they had more ED mental health literacy. Mental health literacy has been defined as "one's knowledge and beliefs about mental disorders which aid their recognition, management and prevention" (Jorm et al., 1997, p. 182).

Evidence suggests that EDs are more common than suspected, and reflect more varied presentations, not just classically defined AN or BN (Worsfold & Sheffield, 2018). Worsfold and Sheffield (2018) argued that EDs are often thought of in their typical presentations, thus when sub-threshold or atypical features manifest, they are viewed as less serious and not requiring special attention. Accordingly, increasing mental health literacy may yield beneficial outcomes, if the consumers of this information are aware of the heterogeneous presentations of EDs and their associated dangers, they may more easily be able to detect early signs and symptoms.

Some parents mentioned wishing to see public service announcements on television or brochures offering the early signs and symptoms of EDs in doctors' offices, grocery stores, and fitness facilities. They shared these hopes with me while they reflected on the months that their own child's AN signs and symptoms went unnoticed or unchallenged. This unavailability of information may speak to a general lack of awareness about EDs among the public, perhaps in part due to the stigma of EDs. Dimitropoulos and colleagues (2016) proposed that the general public believe individuals with EDs can simply (a) pull themselves out of it and (b) only have themselves to blame for their ED. Dimitropoulos and colleagues (2016) conducted 19 qualitative interviews with females receiving intensive inpatient treatment for AN and demonstrated that all participants believed that the general public did not view EDs as an illness. The perception that the public did not consider EDs to be real illnesses often lead participants to conceal their EDs, due to fear of further stigmatization (Dimitropoulos et al., 2016). Further, participants expressed that the general public misjudged the causes of EDs, giving examples that the public believed that people with EDs had "simply a desire to emulate celebrities and models" and engaged in extreme practices for vanity (Dimitropoulos et al., 2016, p. 50). Taken together, the

unfamiliarity and/or misunderstanding that the public has towards those with EDs plays a role in the stigma experience and may contribute to why limited information is readily available. In order to counter this misunderstanding, greater efforts must be made to inform the public, and also specifically parents, so they are informed and can access services should they become concerned about their children's behaviours.

Implications for counselling psychology. While this research has implications for general clinical practice, it also marks a significant contribution to the discipline of counselling psychology. As mentioned in chapter three and in Appendix A, counselling psychology is a discipline that initially focused on career and guidance counselling (Robertson & Borgen, 2016), and has since undergone a transformation where an applied psychology specialization evolved. I believe this is an important development to be aware of, as more recently, counselling psychologists' research and practice has diversified (Haverkamp, Robertson, Cairns, & Bedi, 2011), allowing them to work with and study individuals and phenomena that were traditionally considered outside their scope of practice.

It is my belief that counselling psychologists, with the pre-requisite training in EDs, can be effective clinicians working with this population, while offering holistic perspectives that our training in counselling psychology has uniquely prepared us to have. Though this is my personal position, it appears that graduates from counselling psychology programs infrequently work in settings where EDs specifically are assessed and treated. Recent surveys exploring primary work settings of a sample of Canadian registered psychologists who graduated from counselling psychology programs reported that 35.9% worked in independent practice, followed by 25.6% at academic institutions, usually in the educational/counselling department rather than in departments of psychology. Further, 10% of respondents worked in community settings, and

approximately 5% reported employment in alternative settings such as university wellness centres, K-12 schools, outpatient clinics, hospitals, psychiatric hospitals, forensic clinics, and rehabilitation centres (Bedi, Sinacore, & Christiani, 2016). Taken together, the work identity and settings where counselling psychologists are most often seen are not places typically recognized for the treatment of severe mental disorders, which could further the narrative that counselling psychologists are best equipped to work in areas of positive psychology, developmental, preventative, and person-environment-fit roots (Linley, 2006).

Though this attitude persists within the profession of psychology, more recently, counselling psychology doctoral students have been matched to hospital training sites for their internships, settings premised on the medical model, recognized for the treatment of urgent, severe presenting issues (Haverkamp et al., 2011). With this shift in training practice, perhaps the increasing presence of counselling psychologists in hospital settings will bring about systematic change and alternative approaches to conceptualization, treatment, and research (Haverkamp et al., 2011). It is my hope that individuals graduating from counselling psychology programs do not shy away from places of employment like hospitals or ED clinics, as their clinical training to conceptualize clients using contextual frameworks, cultural competencies, developmental perspectives, and a social justice and advocacy lens will only improve client service and outcomes. Further, all practice disciplines of psychology should (a) prepare their graduates for work in a breadth of clinical fields and (b) encourage continued professional development and training for specific concerns/disorders. This push for continued generalist training with the addition of exposure to specific concerns will allow for more psychologists to offer competent interventions for specific presenting concerns like EDs. Lastly, this shift in

training may also decrease the public's and profession's views that counselling psychologists only work with issues of minimal severity.

Implications for Future Research

The idea behind this research arouse after I completed my master's thesis on the self-disclosure experiences of individuals with EDs. I recognized that no literature from the parental perspective on disclosure/discovery existed, and hence I was called to learning more and filling this critical knowledge gap. Now, what is missing from the literature is the combined perspectives of parents and children with AN. For the current study, ethically I could not determine how to interview both youth and parents and conduct the interview in such a way as to make both parties comfortable with full disclosure. However, if I had been able to do this, I believe even richer accounts of the discovery experience could have been revealed. For example, the recurring experience of children reaching out for help and disclosing to their parents that they were worried about the thoughts they were having, or constantly feeling cold, or feeling nervous to eat their lunches at school in front of others, could have been further investigated. These instances sparked several interpretations from both myself and the parents, however if their children could have commented on what they wished to accomplish by sharing this information with their parents, it may have furthered the conversation and interpretations could have ultimately gone deeper. These instances of asking for help were all followed by a period of time when the child became sicker, more convinced of the AN thoughts, and more compelled to restrict. As AN has a tremendous impact on families, interviewing all members of the family who are involved would allow for dynamic conversing, opportunities for further probing, and would offer researchers insight into the undercurrents of the family unit. Future

research including both parties could be intimately revealing and have significant clinical implications for practitioners working with families.

Limitations

This study examined the unique experiences of parents who discovered their child had AN. Though I believe the interpretations I have presented are meaningful and thought provoking, I acknowledge that the interpretations I have offered may not be identical to interpretations made by other hermeneutic researchers analyzing the same data. In fact, this is not just a limitation of the present study, but of all interpretative work (Moules et al., 2015). Though hermeneutic inquiry has the ability to hold tension and demonstrate that a topic is not quite this, and not quite that, in fact reflecting the complexity of real-life topics, Moules and colleagues (2015) stated, "it could be argued that hermeneutic research is sometimes constrained by its very openness that resists solid conclusion" (p. 180). Accordingly, a hermeneutic study is not able to draw conclusions supported by quantitative statistics and does not seek to make concrete, generalizing claims. Though this is the intended nature of hermeneutics, some researchers and practitioners may find it difficult to see the merit of such methods of inquiry.

Further, while conducting interviews and analyzing transcripts, I used myself as an interpretive vessel, or a research tool, drawing on my call to the topic and the knowledge I have acquired throughout my years in academia and also as a clinician. In using my personal and professional experience to both guide, follow, and query my participants, this could be perceived as a limitation.

Finally, the current study was my first experience with interviews conducted within the hermeneutic research tradition, and although I appreciated the un-structured nature, I acknowledge that not asking the participants the same questions could be a shortcoming. In fact,

I played with various openings to conversations, and tested my interpretations that came about with previous participants as I completed more interviews. Perhaps researchers with more experience in hermeneutic inquiry would have proceeded with the interviews differently, based on knowledge of what typically elicits the richest accounts of the phenomena.

Strengths

This was the first research to examine the discovery experience, from the parental perspective. In doing so, I am pleased and grateful that I spoke to the individuals that I did. Though the aim of participant recruitment and selection of hermeneutic inquiry is not to seek a representative sample that can be generalized, the individuals called to this topic were both male and female, and parents to both sons and daughters with AN. By interviewing parents that discovered that either their son or daughter was experiencing AN and sharing that in this research, my writing and interpretations do not perpetuate the stereotype that only females are affected by AN. In fact, one of the mothers of a son, mentioned this as a primary reason for participating, saying that more research on males impacted by AN is necessary in order to break the stigma. This is an important contribution to the literature.

Further, the recruitment method of allowing parents to complete the interviews as individuals or as a couple is also a strength. This open format of interviewing gave participants a choice, offered partners to reflect and disagree together, and welcomed parents who were not in contact with their child's other parent to be included. I believe that this flexible method of interviewing allowed for participants to be their most comfortable during the interview, thereby granting me access to their most genuine accounts of the experience. Further, this method of interviewing embraced and reflected the modern family, allowing diverse types of parents (e.g., biological, adoptive, step-parents) in various relationship statuses to contribute to the topic.

Finally, a strength I wish to draw attention to is the healing effects that interviews granted to parents reflecting on this topic. During interviews, it struck me that the conversations we were having represented unchartered territory for parents. Parents shared that once they realized their child was in grave medical danger, health professionals took the lead in care, and parents were hurried onto the next process of admitting their children to services. Parents were not granted a moment of pause to collect themselves and then move on. Conversely, the very nature of interviewing served as a remembrance of those fleeting moments of discovery. They created a space and time where memories of discovery could be deeply reflected on. There was no sense of urgency, no being rushed along, and I believe the individuals that I spoke to profoundly appreciated this. In fact, numerous parents thanked me for embarking on this research, as they felt that the voices of parents were missing and often times skipped over all together.

Summary: Pressing the Shutter Button

As my analysis and interpretation of this topic comes to an end, I am captured in the raw and moving experiences of parents who have discovered their child has AN. Discovery represents the culmination of many moving, seemingly unrelated pieces, finally coming together. Simply put, during the discovery, children with AN finally come into focus.

References

A shadow of your former self. (n.d.). *Cambridge dictionary*. Retrieved from https://dictionary.cambridge.org/dictionary/english/a-shadow-of-your-former-self

Abram, D. (1996). *The spell of the sensuous: Perception and language in a more than human world.* New York, NY: Vintage Books.

Adam, D. (2013). Mental health: On the spectrum. *Nature, 496*(7446), 416-418. doi: 10.1038/496416a

Adlam, J. (2015). Refusal and coercion in the treatment of severe anorexia nervosa: The antigone paradigm. *Psychodynamic Practice*, *21*, 19-35. http://dx.doi.org/10.1080/14753634.2014.989714

Aletheia. (n.d.). *Online etymology dictionary*. Retrieved from http://www.etymonline.com/index.php?term=Alethea

Ambiguity. (n.d.). *Cambridge dictionary*. Retrieved from https://dictionary.cambridge.org/dictionary/english/ambiguity#dataset-cacd

Ambiguity. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriam-webster.com/dictionary/ambiguity

Ambiguous. (n.d.). *Online etymology dictionary*. Retrieved from http://www.etymonline.com/index.php?term=ambiguity

American Psychiatric Association [APA] (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Arlington, VA: American Psychiatric Association.

Anastasiadou, D., Cuellar-Flores, I., Sepulveda, A. R., & Graell, M. (2014). The relationship between dysfunctional patterns of families response to the illness and symptom severity in adolescent patients with anorexia nervosa at illness onset: A gender-specific approach.

In *8th Annual South-East European Doctoral Student Conference* (p. 377). Retrieved from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.697.6983&rep=rep1&type=pdf#page=374

Anastasiadou, D., Medina-Pradas, C., Sepulveda, A. R., & Treasure, J. (2014). A systematic review of family caregiving in eating disorders. *Eating Behaviors*, *15*, 464-477. https://dx.doi.org/10.1016/j.eatbeh.2014.06.001

Anderluh, M. B., Tchanturia, K., & Rabe-Hesketh, S. (2003). Childhood obsessive compulsive personality traits in adult women with eating disorders: Defining a broader eating disorder phenotype. *American Journal of Psychiatry*, *160*, 242–7. https://doi.org/10.1176/appi.ajp.160.2.242

Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Archives of General Psychiatry, 68,* 724–731. doi:10.1001/archgenpsychiatry.2011.74

Bardach, N. S., Coker, T. R., Zima, B. T., Murphy, J. M., Knapp, P., Richardson, L. P., … Smith, R. M. (2014). Common and costly hospitalizations for pediatric mental health disorders. *Pediatrics*, *133*, 602-609. doi:10.1542/peds.2013-3165

Basile, B. (2004). Self-disclosure in eating disorders. *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity*, *9*, 217-223. doi:10.1007/BF03325070

Becker, A. E., Grinspoon, S. K., Kilbanski, A., & Herzog, D. B (1999). Eating disorders. *North England Journal of Medicine, 340*, 1092–1098. doi: 10.1056/NEJM199904083401407

Becker, A. E., Thomas, J. J., Franko, D. L., & Herzogm D. B. (2005). Disclosure patterns of

eating and weight concerns to clinicians, educational professionals, family and peers. *International Journal of Eating Disorders*, *38*, 18-23. doi:10.1002/eat.20141

Bedi, R. P., Haverkamp, B. E., Beatch, R., Cave, D. G., Domene, J. F., Harris, G. E., & Mikhail, A. M. (2011). Counselling psychology in a Canadian context: Definition and description. *Canadian Psychology/Psychologie Canadienne*, *52*, 128-138. doi: 10.1037/a0023186

Bedi, R.R., Sinacore, A., & Christiani, K. D. (2016) Counselling psychology in Canada, *Counselling Psychology Quarterly*, *29*, 150-162. doi:10.1080/09515070.2015.1128398

Berkman, N. D., Lohr, K. N., & Bulik, C. M. (2007). Outcomes of eating disorders: A systematic review of the literature. *International Journal of Eating Disorders*, *40*, 293-309. doi: 10.1002/eat.20369

Blondin, S., Meilleur, D., Taddeo, D., & Frappier, J. (2019). Caregiving experience and expressed emotion among parents of adolescents suffering from anorexia nervosa following illness onset, *Eating Disorders*, *6*, 1-18. doi: 10.1080/10640266.2018.1553431

Boss, P. (2006). *Loss, trauma, and resilience. Therapeutic work with ambiguous loss.* New York, NY: W. W. Norton.

Brandom, R. (1983). Heidegger's categories in "Being and Time". *The Monist*, 66, 387-409. Retrieved from http://www.jstor.org.ezproxy.lib.ucalgary.ca/stable/pdf/27902817.pdf?refreqid=excelsior%3Ae62c61909c451fba9ff35f9ce627d690

Brown, H. (2010). *Brave girl eating: A family's struggle with anorexia*. New York, NY: HarperCollins.

Brown, H. (2011, February 11). *How I saved my daughter's life: A mother's story of anorexia*.

Retrieved from http://www.telegraph.co.uk/news/health/children/8345074/How-I-saved-my-daughters-life-a-mothers-story-of-anorexia.html

Bulik, C. M., Brownley, K. A., Shapiro, J. R., & Berkman, N. (2012). Anorexia. In M. Hersen & P. Sturmey (Eds.), *Handbook of evidence-based practice in clinical psychology, child and adolescent disorders child and adolescent disorders* (pp. 575-597). Chichester, UK: Wiley.

Byrne, S., Wade, T., Hay, P., Touyz, S., Fairburn, C. G., Treasure, J., ... & Crosby, R. D. (2017). A randomised controlled trial of three psychological treatments for anorexia nervosa. *Psychological Medicine*, *47*, 2823-2933. https://doi.org/10.1017/S0033291717001349

Caputo, J. D. (2015). Foreword: The wisdom of hermeneutics. In N.J. Moules, G. McCaffrey, J.C. Field, & C.M. Laing, *Conducting hermeneutic research: From philosophy to practice* (pp. ix- xiii). New York, NY: Peter Lang.

Cohen, A., & Bai, H. (2015). Suffering loves and needs company: Buddhist and Daoist perspectives on the counselor as companion (pp. 53- 66). In D. W. Jardine, C. Gilham, & G. McCaffrey (Eds.), *On the pedagogy of suffering: Hermeneutic and Buddhist meditations.* New York, NY: Peter Lang.

Component. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriam-webster.com/dictionary/components

Confront. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriamwebster.com/dictionary/confront

Consume. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriam-webster.com/dictionary/consumed

Cool, C. (2019). Three essential steps to my recovery: Rage, reclamation, relationship. *Gürze-Salucore Eating Disorders Resource Catalogue*. Retrieved from https://www.edcatalogue.com/three-essential-steps-recovery-rage-reclamation-relationship/

Cottee-Lane, D., Pistrang, N., & Bryant-Waugh, R. (2004). Childhood onset anorexia nervosa: The experience of parents. *European Eating Disorders Review*, *12*, 169-177. https://doi.org/10.1002/erv.560

Craigie, J., Hope, T., Tan, J., Stewart, A., & McMillan, J. (2013). Agency, ambivalence and authenticity: The many ways in which anorexia nervosa can affect autonomy. *International Journal of Law in Context*, *9*, 20-36. doi:10.1017/S1744552312000456

De Beauvoir, S. (1948/2015). *The ethics of ambiguity*. New York, NY: Philosophical Library.

De la Rie, S. M., Van furth, E. F., De Koning, A., Noordenbos, G., & Donker, M. C. (2005). The quality of life of family caregivers of eating disorder patients. *Eating Disorders*, *13*, 345-351. http://dx.doi.org/10.1080/10640260591005236

Dimitropoulos, G., Klopfer, K., Lazar, L., & Schacter, R. (2009). Caring for a sibling with anorexia nervosa: A qualitative study. *European Eating Disorders Review*, *17*, 350-365. https://doi.org/10.1002/erv.937

Dimitropoulos, G., Freeman, V. E., Bellai, K., & Olmsted, M. (2013). Inpatients with severe anorexia nervosa and their siblings: Non-shared experiences and family functioning. *European Eating Disorders Review*, *21*, 284-293. doi: 10.1002/erv.2230

Dimitropoulos, G., Freeman, V. E., Muskat, S., Domingo, A., & McCallum, L. (2016). “You

don't have anorexia, you just want to look like a celebrity": Perceived stigma in individuals with anorexia nervosa. *Journal of Mental Health*, *25*, 47-54. doi:10.3109/09638237.2015.1101422

Dishonesty. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriamwebster.com/dictionary/dishonesty

Doka, K. (2014). Counseling clients through the crisis of diagnosis. In *Counseling individuals with life-threatening illness* (2nd ed.). New York, N.Y.: Springer.

Doka, K. J., & Aber, R. A. (2002). Psychosocial loss and grief. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 217-231). Chicago, IL: Research Press.

Fidyk, A. (2015). A black blessing. In D. W. Jardine, C. Gilham, & G. McCaffrey (Eds.), *On the pedagogy of suffering: Hermeneutic and Buddhist meditations* (pp. 101-106). New York, NY: Peter Lang.

Fiedler, C. (2011). *Robbery and redemption: Cancer as identity theft*. Retrieved from https://ebookcentral-proquest-com.ezproxy.lib.ucalgary.ca

Field, J. C. (2017). Lecture on hermeneutics. Personal collection of (J. C. Field), University of Calgary, Calgary, AB, Canada.

Finlay, L. (2015). Sensing and making sense: Embodying metaphor in Relational-Centered psychotherapy. *The Humanistic Psychologist, 43*(4), 338-353. doi: 10.1080/08873267.2014.993070

Frank, G. K. W. (2016). The perfect storm - A bio-psycho-social risk model for developing and maintaining eating disorders. *Frontiers in Behavioral Neuroscience*, *10*, 44. doi: 10.3389/fnbeh.2016.00044

Gadamer, H-G. (1960/2013). *Truth and method* (Bloomsbury revelations; J. Weinsheimer & D. G. Marshall, Trans.). London, UK: Bloomsbury.

Gadamer, H-G. (1996). *The enigma of health*. Stanford, CA: Stanford University Press.

Gadamer, H-G. (2007). *The Gadamer reader: A bouquet of the later writings* (R.E. Palmer, Ed. & Trans.). Evanston: IL. Northwestern University Press.

Gailey, J. A. (2009). "Starving is the most fun a girl can have": The pro-ana subculture as edgework. *Critical Criminology*, *17*, 93-108. doi:10.1007/s10612-009-9074-z

George, L., Thornton, C., Touyz, S. W., Waller, G., & Beumont, P. J. (2004). Motivational enhancement and schema-focused cognitive behaviour therapy in the treatment of chronic eating disorders. *Clinical Psychologist*, *8*, 81-85. doi: 10.1080/13284200412331304054

Gisladottir, M., Treasure, J., & Svavarsdottir, E. K. (2017). Effectiveness of therapeutic conversation intervention among caregivers of people with eating disorders: Quasi-experimental design. *Journal of Clinical Nursing*, *26*, 735-750. doi: 10.1111/jocn.13412

Goddard, E., & Treasure, J. (2013). Anxiety and social-emotional processing in eating disorders: Examination of family trios. *Cognitive Therapy and Research*, *37*, 890-904. doi: 10.1007/s10608013-9535-2

Gray, E. K., Murray, H. B., & Eddy, K. T. (2015). Diagnosing anorexia nervosa. In L. Smolak & M. P. Levine (Eds.), *The Wiley handbook of eating disorders, First Edition* (pp. 93-104). West Sussex, UK: John Wiley & Sons. doi: 10.1002/9781118574089.ch8

Grice, D. E., Halmi, K. A., Fichter, M. M., Strober, M., Woodside, D. B., Treasure, J. T., ... & Kaye, W. H. (2002). Evidence for a susceptibility gene for anorexia nervosa on chromosome 1. *The American Journal of Human Genetics*, *70*(3), 787-792. doi: 10.1086/339250

Grondin, J. (1994). *Introduction to philosophical hermeneutics*. New Haven, NY: Yale University Press.

Hamkins, S. (2005). Book review. Biting the hand that starves you: Inspiring resistance to anorexia/bulimia. *Psychiatric Services. Retrieved from https://ps.psychiatryonline.org/doi/full/10.1176/appi.ps.56.9.1168*

Hammond, C. (2016). *Can quicksand really suck you to your death*? http://www.bbc.com/future/story/20160323-can-quicksand-really-suck-you-to-your-death

Haverkamp, B. E., Robertson, S. R., Cairns, S. L., & Bedi, R. P. (2011). Professional issues in Canadian counseling psychology: Identity, education, and professional practice. *Canadian Psychology/Psychologie canadienne*, *52*, 256–264. http://dx.doi.org/10.1037/a0025214

Hebebrand, J., Albayrak, O., Adan, R., Antel, J., Dieguez, C., de Jong, J., ... Dickson, S. L. (2014). "Eating addiction", rather than "food addiction", better captures addictive-like eating behavior. *Neuroscience & Biobehavioral Reviews*, *47*, 295–306. doi: 10.1016/j.neubiorev.2014.08.016

Heidegger, M. (1971). Building dwelling thinking. *Poetry, Language, Thought*, *154*. Retrieved from http://faculty.arch.utah.edu/miller/4270heidegger.pdf

Hermeneutic. (n.d.). *Online etymology dictionary*. Retrieved from http://www.etymonline.com/index.php?allowed_in_frame=0&search=Hermeneutic

Higgins, A., & Cahn, S. (2018). Detection of anorexia nervosa in primary care, *Eating Disorders*, *26*(3), 213-228, doi: 10.1080/10640266.2017.1397419\

Highet, N., Thompson, M., & King, R. M. (2005). The experience of living with a person with an eating disorder: The impact on the carers. *Eating Disorders*, *13*(4), 327-44.

10.1080/10640260591005227

Hoek, H. W. (2006). Incidence, prevalence and mortality of anorexia nervosa and other eating disorders. *Current Opinion in Psychiatry*, *19*, 389-394. doi: 10.1097/01.yco.0000228759.95237.78

Honey, A., Boughtwood, D., Clarke, S., Halse, C., Kohn, M., & Madden, S. (2008). Support for parents of children with anorexia: What parents want. *Eating Disorders, 16*, 40-51. http://dx.doi.org/10.1080/10640260701773447

Honey, A., Clarke, S., Halse, C., Kohn, M., & Madden, S. (2006). The influence of siblings on the experience of anorexia nervosa for adolescent girls. *European Eating Disorders Review*, *14*, 315-322. doi: 10.1002/erv.713

Horesh, N., Apter, A., Ishai, J., Danziger, Y., Miculincer, M., Stein, D., … Minouni, M. (1996). Abnormal psychosocial situations and eating disorders in adolescence. *Journal of the American Academy of Child & Adolescent Psychiatry*, *35*, 921-927. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/8768353

Hubert Lacey, J., & Sly, R. (2015). Severe and enduring anorexia nervosa: Diagnosis, features, and radical new treatment approaches. In L. Smolak & M. P. Levine (Eds.), *The Wiley handbook of eating disorders* (pp. 142-156*)*, West Sussex, UK: John Wiley & Sons.

Jacobi, C., Fittig, E., Bryson, S. W., Wilfley, D., Kraemer, H. C., & Taylor, C. B. (2011). Who's really at risk? Identifying risk factors for subthreshold and full syndrome eating disorders in a high-risk sample. *Psychological Medicine, 41*, 1939-1949. doi: 10.1017/S0033291710002631

Jardine, D. W. (2015). Some introductory words for two little earth cousins In D. W. Jardine, C.

Gilham, & G. McCaffrey (Eds.), *On the pedagogy of suffering: Hermeneutic and Buddhist meditations* (pp. 83-86). New York, NY: Peter Lang.

Jardine, D. W. (2015). This is why we read. This is why we write. In D. W. Jardine, C. Gilham, & G. McCaffrey (Eds.), *On the pedagogy of suffering: Hermeneutic and Buddhist meditations* (pp. 87-88). New York, NY: Peter Lang.

Jardine, D. W., McCaffrey, G, & Gilham, C. (2015). "Just this once": An introduction to the pedagogy of suffering. In D. W. Jardine, C. Gilham, & G. McCaffrey (Eds.), *On the pedagogy of suffering: Hermeneutic and Buddhist meditations* (pp. 1-5). New York, NY: Peter Lang.

Jorm, A., Korten, A. E., Jacomb, P. A., Christensen, H., Rodgers, B., & Penelope, P. (1997). Mental health literacy: A survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. *Medical Journal of Australia*, *4*, 166-182. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/9066546

Keel, P. K., Dorer, D. J., Eddy, K. T., Franko, D., Charatan, D. L., & Herzog, D. B. (2003). Predictors of mortality in eating disorders. *Archives of General Psychiatry*, *60*, 179-183. doi: 10.1001/archpsyc.60.2.179

Keitel, M. A., Parisi, M., Whitney, J. L., & Stack, L. F. (2010). Salient stressors for mothers of children and adolescents with anorexia nervosa. *Eating Disorders*, *18*, 435-44. https://doi.org/10.1080/10640266.2010.511937

Kempa, M. L., & Thomas, A. J. (2000). Culturally sensitive assessment and treatment of eating disorders, *Journal of Eating Disorders*, *8*, 17- 30, doi: 10.1080/10640260008251209

Khalsa, S. S., Portnoff, L. C., McCurdy-McKinnon, D., & Feusner, J. D. (2017). What happens

after treatment? A systematic review of relapse, remission, and recovery in anorexia nervosa. *Journal of Eating Disorders*, *5*(20), 1-12. doi: 10.1186/s40337-017-0145-3

Klump, K. L., Bulik, C. M., Kaye, W. H., Treasure, J., & Tyson, E. (2009). Academy for eating disorders position paper: Eating disorders are serious mental illnesses. *International Journal of Eating Disorders*, *42*, 97-103. doi: 10.1002/eat.20589

Klump, K. L., Miller, K. B., Keel, P. K., McGue, M., & Iacono, W. G. (2001). Genetic and environmental influences on anorexia nervosa syndromes in a population-based twin sample. *Psychological Medicine*, *31*, 737-740. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/11352375

Kortegaard, L. S., Hoerder, K., Joergensen, J., Gillberg, C., & Kyvik, K. O. (2001). A preliminary population-based twin study of self reported eating disorder. *Psychological Medicine*, *31*, 361-365. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/11232922

Kyriacou, O., Treasure, J., & Schmidt, U. (2008). Understanding how parents cope with living with someone with anorexia nervosa: Modelling the factors that are associated with carer distress. *International Journal of Eating Disorders, 41*, 233-242. doi: 10.1002/eat.20488

Lakeman, R., McGowan, P., MacGabhann, L., Parkinson, M., Redmond, M., Sibitz, I., … & Walsh, J. (2012). A qualitative study exploring experiences of discrimination associated with mental-health problems in Ireland. *Epidemiology and Psychiatric Sciences*, *21*, 271-279. doi:10.1017/S2045796012000017

Le Grange, D., Binford, R., & Loeb, K. L. (2005). Manualized family-based treatment for anorexia nervosa: a case series. *Journal of the American Academy of Child & Adolescent Psychiatry*, *44*, 41-46. https://doi.org/10.1097/01.chi.0000145373.68863.85

Le Grange, D., Hughes, E. K., Court, A., Yeo, M., Crosby, R.D., & Sawyer, S. M. (2016). Randomized clinical trial of parent-focused treatment and family-based treatment for adolescent anorexia nervosa. *Journal of the American Academy of Child and Adolescent Psychiatry*, *55*, 683-692. doi: 10.1016/j.jaac.2016.05.007.

Le Grange, D., Lock, J., Accurso, E. C., Agras, S. W., Darcy, A., Forsberg, S., & Bryson, S. (2014). Relapse from remission at two- to four-year follow-up in two treatments for adolescent anorexia nervosa. *Journal of the American Academy of Child and Adolescent Psychiatry*, *53*, 1162-1167. doi: 10.1016/j.jaac.2014.07.014

Le Grange, D., Lock, J., Loeb, K., & Nicholls, D. (2010). Academy for eating disorders position paper: The role of the family in eating disorders. *International Journal of Eating Disorders*, *43*(1), 1-5. doi: 10.1002/eat.20751

Le Grange, D., Tibbs, J., & Selibowitz, J. (1995). Eating attitudes, body shape, and self disclosure in a community sample of adolescent girls and boys. *Eating Disorders*, *3*, 253-264. doi:10.1080/10640269508249169

Liminal. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriam-webster.com/dictionary/liminal2

Linley, P. A. (2006). Counseling psychology's positive psychological agenda: A model for integration and inspiration. *The Counseling Psychologist*, *34*, 313-322. https://doi.org/10.1177/0011000005284393

Linville, D., Brown, T., & O'Neil, M. (2012). Medical providers' self perceived knowledge and skills for working with eating disorders: A national survey. *Eating Disorders*, *20*, 1-13. doi:10.1080/10640266.2012.635557

Lock, J., & Le Grange, D. (2018). Family-based treatment: Where are we and where should we

be going to improve recovery in child and adolescent eating disorders. *International Journal of Eating Disorders,* 1-7. https://doi.org/10.1002/eat.22980

Lock, J, Le Grange, D., Agras, S., & Dare, C. (2001). *Treatment manual for anorexia nervosa: A family-based approach*. New York: NY. The Guilford Press.

Lock, J., Le Grange, D., Agras, W. S., Moye, A., Bryson, S. W., & Jo, B. (2010). Randomized clinical trial comparing family-based treatment with adolescent-focused individual therapy for adolescents with anorexia nervosa. *Archives of General Psychiatry*, *67*, 1025-1032. doi: 10.1001/archgenpsychiatry.2010.128.

Loeb, K., & Le Grange, D. (2009). Family based treatment for adolescent eating disorders: Current status, new applications and future directions. *International Journal of Child and Adolescent Health*, *1*, 243-254. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2828763/pdf/nihms87663.pdf

McCormack, C., & McCann, E. (2015). Caring for an adolescent with anorexia nervosa: Parent's views and experiences. *Archives of Psychiatric Nursing*, *29*, 143-147. doi: 10.1016/j.apnu.2015.01.003

Micali, N., Hagberg, K. W., Petersen, I., & Treasure, J. L. (2013). The incidence of eating disorders in the UK in 2000–2009: Findings from the General Practice Research Database. *British Medical Journal*, *3*, 1-8. doi: 10.1136/bmjopen-2013-002646.

Minuchin, S., Rosman, B. L., & Baker, L. (1978). *Psychosomatic families: Anorexia nervosa in context*. Cambridge, MA: Harvard University Press.

Morgan, J. F., Reid, F., & Lacey, J. H. (1999). The SCOFF questionnaire: Assessment of a new screening tool for eating disorders. *British Medical Journal, 319*, 1467-1468. doi:10.1136/bmj.319.7223.1467

Moules, N. J. (2002). Hermeneutic inquiry: Paying heed to history and Hermes. An ancestral, substantive, and methodological tale. *International Journal of Qualitative Methods*, *1*, 1-21. Retrieved from http://journals.sagepub.com/doi/full/10.1177/160940690200100301

Moules, N. J. (2015). Aletheia - - Remembering and enlivening. *Journal of Applied Hermeneutics*. Retrieved from https://journalhosting.ucalgary.ca/index.php/jah/article/view/53255/40616

Moules, N. J., & McCaffrey, G. (2017). *Lecture on Some history of hermeneutics*. Personal collection of (N. J. Moules & G. McCaffrey), University of Calgary, Calgary, AB, Canada.

Moules, N. J., McCaffrey, G., Field, J. C., & Laing, C. M. (2015). *Conducting hermeneutic research: From philosophy to practice.* New York, NY: Peter Lang.

Murnen, S. K., Smolak, L., Mills, J. A., & Good, L. (2003). Thin, sexy women and strong, muscular men: Grade-school children's responses to objectified images of women and men. *Sex Roles*, *49*, 427-437. Retrieved from https://link-springer-com.ezproxy.lib.ucalgary.ca/content/pdf/10.1023%2FA%3A1025868320206.pdf

Murphy, F., Troop, N. A., & Treasure, J. L. (2000). Differential environmental factors in anorexia nervosa: A sibling pair study. *British Journal of Clinical Psychology, 39*, 193-203. doi:10.1348/014466500163211

Murray, S. B. (2019). Updates in the treatment of eating disorders in 2018: A year in review in eating disorders: *Eating Disorders*: *The Journal of Treatment & Prevention*, *27*, 6-17. https://doi.org/10.1080/10640266.2019.1567155

Murray, S. B., Loeb, K. L., & Le Grange, D. (2018). Treatment outcome reporting in anorexia nervosa: Time for a paradigm shift? *Journal of Eating Disorders*, *6*(10).

https://doi.org/10.1186/s40337-018-0195-1

Muscari, M. (2002). Effective management of adolescents with anorexia and bulimia. *Journal of Psychosocial Nursing and Mental Health Services, 40*, 22-31. doi: 10.3928/0279-3695-20020201-09

National Institute for Health and Care Excellence (NICE). (2017). Eating disorders: Recognition and treatment. UK. Available at: https://www.nice.org.uk/guidance/ng69/ resources/eating-disorders-recognition-and-treatment-pdf-1837582159813.

Nordbø, R. H. S., Espeset, E. M. S., Gulliksen, K. S., Skårderud, F., & Holte, A. (2006). The meaning of self-starvation: A qualitative study of patients' perception of anorexia nervosa. *The International Journal of Eating Disorders*, *39*, 556-564. doi: 10.1002/eat.20276

Nordbø, R. H., Espeset, E., Gulliksen, K. S., Skårderud, F., Geller, J., & Holte, A. (2012). Reluctance to recover in anorexia nervosa. *European Eating Disorders Review*, *20*, 60-67. doi: 10.1002/erv.1097

North, C., Gowers, S., & Byram, V. (1995). Family functioning in adolescent anorexia nervosa. *The British Journal of Psychiatry*, *167*(5), 673-678. https://doi.org/10.1192/bjp.167.5.673

Palmer, R. E. (Ed. & Trans.) (2007). *The Gadamer reader: A bouquet of later writings.* Evanston, IL: Northwestern University Press.

Patel, S., Shafer, A., Brown, J., Bulik, C., & Zucker, N. (2014). Parents of children with eating disorders: Developing theory-based health communication messages to promote caregiver well-being. *Journal of Health Communication*, *19*, 593-608. doi: 10.1080/10810730.2013.821559

Polivy, J., & Herman, C. P. (2002). Causes of eating disorders. *Annual Review of Psychology*, *53*(1), 187-213. Retrieved from https://pdfs.semanticscholar.org/4e48/9ca5f5de4239a60e3eb10e489238305c4e80.pdf

Quong, R., & Chen, S. P. (2018). A meta-ethnography of the experience for caregivers of individuals with eating disorders. *Current Psychiatry Reviews*, *14*(1), 33-46. doi: 10.2174/1573400514666180403124554

Rhind, C., Salerno, L., Hibbs, R., Micali, N., Schmidt, U., Gowers, S., ... & Lo Coco, G. (2016). The objective and subjective caregiving burden and caregiving behaviours of parents of adolescents with anorexia nervosa. *European Eating Disorders Review*, *24*(4), 310-319. doi: 10.1002/erv.2442

Rodgers, R., Paxton, F., & McLean, S. (2014). A biopsychosocial model of body image concerns and disordered eating in early adolescent girls. *Journal of Youth and Adolescence, 43*(5), 814-823. doi: 10.1007/s10964-013-0013-7

Ryan, C. J., & Callaghan, S. (2014). Treatment refusal in anorexia nervosa: The hardest of cases. *Journal of Bioethical Inquiry*, *11*, 43-45. doi: 10.1007/s11673-013-9498-8

Sandelowski, M. (2004). Using qualitative research. *Qualitative Health Research*, *14*, 1366-1386. Retrieved from http://journals.sagepub.com/doi/abs/10.1177/1049732304269672

Schlegl, S., Quadflieg, N., Löwe, B., Cuntz, U., & Voderholzer, U. (2014). Specialized inpatient treatment of adult anorexia nervosa: Effectiveness and clinical significance of changes. *BioMed Central Psychiatry*, *14*, 258. https://doi.org/10.1186/s12888-014-0258-z

Schulte, E. M., Potenza, M. N., & Gearhardt, A. N. (2017). A commentary on the “eating addiction” versus “food addiction” perspectives on addictive-like food consumption. *Appetite*, *115*, 9-15. http://dx.doi.org/10.1016/j.appet.2016.10.033.

Schultz, P. (2007). Exquisite with agony. *Failure: Poems* (p. 19). New York, NY: Mariner Books.

Self-preservation. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriam-webster.com/dictionary/self-preservation

Sepulveda, A. R., Kyriacou, O., & Treasure, J. (2009). Development and validation of the Accommodation and Enabling Scale for Eating Disorders (AESED) for caregivers in eating disorders. *BMC Health Services Research*, *9*, 171. https://doi.org/10.1186/1472-6963-9-171

Shapiro, C. M. (2012). Health psychology research focus: Eating disorders: Causes, diagnosis and treatments. New York, NY: Nova Biomedical.

Shoebridge, P., & Gowers, S. G. (2000). Parental high concern and adolescent-onset anorexia nervosa: A case-control study to investigate direction of causality. *British Journal of Psychiatry*, *176*, 132-137. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/10755049

Slade, P. (1982). Towards a functional analysis of anorexia nervosa and bulimia nervosa. *British Journal of Clinical Psychology*, *21*(3), 167-179. http://dx.doi.org/10.1111/j.2044-8260.1982.tb00549.x

Starzomska, M., & Tadeusiewicz, R. (2016). Pitfalls in anorexia nervosa research: The risk of artifacts linked to denial of illness and methods of preventing them. *Psychiatria Danubina*, *28*, 202-210. Retrieved from http://scholar.googleusercontent.com/scholar?q=cache:lYCOXiiFl5UJ:scholar.google.com/+Pitfalls+in+anorexia+nervosa+research:+The+risk+of+artifacts+linked+to+denial+of+illness+and+methods+of+preventing+them&hl=en&as_sdt=0,5

Steinhausen, H. C. (2002). The outcome of anorexia nervosa in the 20th century. *American Journal of Psychiatry*, *159*, 1284-1293. Retrieved from http://www.saegre.org.ar/biblioteca/arbol_bibliografico/agosto2005/1284_anorexia_outcome.pdf

Steinhausen, H. C. (2008). Outcome of eating disorders. *Child and Adolescent Psychiatric Clinics of North America*, *18*, 225-242. doi:10.1016/j.chc.2008.07.013

Stice, E., & Desjardins, C. D. (2018). Interactions between risk factors in the prediction of onset of eating disorders: Exploratory hypothesis generating analyses. *Behaviour Research and Therapy*, *105*, 52-62. https://doi.org/10.1016/j.brat.2018.03.005

Stoving, R. K., Andries, A., Brixen, K., Bilenberg, N., & Horder, K. (2011). Gender differences in outcome of eating disorders: A retrospective cohort study. *Psychiatry Research*, *186*, 362-366. doi: 10.1016/j.psychres.2010.08.005

Striegel-Moore, R. H., & Bulik, C. M. (2007). Risk factors for eating disorders. *American Psychologist*, *62*, 181-198. doi: 10.1037/0003-066X.62.3.181

Strober, M., Freeman, R., & Lampert, C. (2000). Controlled family study of anorexia nervosa and bulimia nervosa: Evidence of shared liability and transmission of partial syndromes. *American Journal of Psychiatry*, *157*, 393-401. doi: 10.1176/appi.ajp.157.3.393

Suffer. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriam-webster.com/dictionary/suffer

Sutandar-Pinnock, K., Blake, W. D., & Carter, J. C. (2003). Perfectionism in anorexia nervosa: A 6–24 month follow-up study. *International Journal of Eating Disorders*, *33*, 225-229. doi: 10.1002/eat.10127

Top Superstitions Explained. (n.d.). *CBC Doc Zone*. Retrieved from

https://www.cbc.ca/doczone/m_features/top-superstitions-explained

Treasure, J., & Russell, G. (2011). The case for early intervention in anorexia nervosa: Theoretical exploration of maintaining factors. *The British Journal of Psychiatry, 199*, 5-7. doi: 10.1192/bjp.bp.110.087585

Treasure, J., Murphy, T., Szmukler, G., Todd, G., Gavan, K., & Joyce, J. (2001). The experience of caregiving for severe mental illness: A comparison between anorexia nervosa and psychosis. *Social Psychiatry and Psychiatric Epidemiology, 36*, 343-34. https://doi-org.ezproxy.lib.ucalgary.ca/10.1007/s001270170039

Treasure, J., & Schmidt, U. (2013). The cognitive-interpersonal maintenance model of anorexia nervosa revisited: a summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *Journal of Eating Disorders*, *1*(1), 13. https://doi.org/10.1186/2050-2974-1-13

Treasure, J., Sepulveda, A. R., MacDonald, P., Whitaker, W., Lopez, C., Zabala, M., ... & Todd, G. (2008). The assessment of the family of people with eating disorders. *European Eating Disorders Review*, *16*, 247-255. doi: 10.1002/erv.859

Treasure, J., Sepulveda, A. R., Whitaker, W., Todd, G., Lopez, C., & Whitney, J. (2007). Collaborative care between professionals and non-professionals in the management of eating disorders: A description of workshops focused on interpersonal maintaining factors. *European Eating Disorders Review, 15*, 24-34. doi: 10.1002/erv.758

Treasure, J., Stein, D., & Maguire, S. (2015). Has the time come for a staging model to map the course of eating disorders from high risk to severe enduring illness? An examination of the evidence. *Early Intervention in Psychiatry*, *9*, 173-184. doi:10.1111/eip.12170

Ubiquitous. (n.d.) *Merriam-Webster's online dictionary*. Retrieved from

https://www.merriam-webster.com/dictionary/ubiquitous

Uehara, T., Kawashima, Y., Goto, M., Tasaki, S. I. & Someya, T. (2001). Psychoeducation for the families of patients with eating disorders and changes in expressed emotion: A preliminary study. *Comprehensive Psychiatry, 42*, 132-138. https://doi.org/10.1053/comp.2001.21215

Uncertain. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriam-webster.com/dictionary/uncertain

Vandereycken, W. (2006). Denial of illness in anorexia nervosa – A conceptual review: Part 1 diagnostic significance and assessment. *European Eating Disorders Review*, *14*, 341-351. doi:10.1002/erv.721

Vandereycken, W., & Van Vreckem, E. (1992). Siblings of patients with an eating disorder. *International Journal of Eating Disorders, 12*, 273-280. doi:10.1002/1098108X(199211)12:3 < 273::AIDEAT2260120307 > 3.0.CO;2-K

Von Holle, A., Poyastro Pinheiro, A., Thornton, L. M., Klump, K. L., Berrettini, W. H., Brandt, H., ... & Johnson, C. (2008). Temporal patterns of recovery across eating disorder subtypes. *Australian & New Zealand Journal of Psychiatry*, *42*(2), 108-117. https://doi.org/10.1080/00048670701787610

Von Ranson, K. M., & Wallace, L. M. (2014). Eating disorders. In E. J. Mash & R. A. Barkley (Eds.), *Child psychopathology* (3rd ed.; pp. 801-847). New York: NY. The Guilford Press.

Voriadaki, T., Simic, M., Espie, J., & Eisler, I. (2015). Intensive multi-family therapy for adolescent anorexia nervosa: adolescents' and parents' day-to-day experiences. *Journal of Family Therapy*, *37*, 5-23. doi: 10.1111/1467-6427.12067

Wade, T., Bulik, C. M., Neale, M., & Kendler, K. S. (2000). Anorexia nervosa and major

depression: Shared genetic and environmental risk factors. *American Journal of Psychiatry*, *157*, 469-471. doi: 10.1176/appi.ajp.157.3.469

Walker, K. (2013, September 26). *Are you certain you'd spot it if your daughter was starving herself? Ruth's story is a truly terrifying wake-up call*. Retrieved from http://www.dailymail.co.uk/femail/article-2432453/Anorexia-Nervosa-Certain-youd-spot-daughter-starving-Ruths-story-wake-call.html

Welch, S. L., Doll, H. A., & Fairburn, C. G. (1997). Life events and the onset of bulimia nervosa: A controlled study. *Psychological Medicine*, *27*, 515-522. http://dx.doi.org/10.1017/S0033291796004370

Whitney, J., Murray, J., Gavan, K., Todd, G., Whitaker, W., & Treasure, J. (2005). Experience of caring for someone with anorexia nervosa: Qualitative study. *British Journal of Psychiatry, 187*, 444–449. doi: 10.1192/bjp.187.5.444

Williams, E. P., Russell-Mayhew, S., & Ireland, A. (2018). Disclosing an eating disorder: A situational analysis of online accounts. *The Qualitative Report*, *23*(4), 914-931. Retrieved from https://nsuworks.nova.edu/tqr/vol23/iss4/14

Williams, E. P., Russell-Mayhew, S., Moules, N. J., & Dimitropoulos, G. (2018). Not quite this and not quite that: Anorexia nervosa, counselling psychology, and hermeneutic inquiry in a tapestry of ambiguity. *Journal of Applied Hermeneutics, 0*. Retrieved from http://jah.journalhosting.ucalgary.ca/jah/index.php/jah/article/view/165

Williams, S., & Reid, M. (2010). Understanding the experience of ambivalence in anorexia nervosa: The maintainer's perspective. *Psychology and Health*, *25*, 551-567. doi: 10.1080/08870440802617629

Woerwag-Mehta, S., & Treasure, J. (2008). Causes of anorexia nervosa. *Psychiatry*, *7*(4), 147-

151. https://doi.org/10.1016/j.mppsy.2008.02.010

Worsfold, K. A., & Sheffield, J. K. (2018). Eating disorder mental health literacy: What do psychologists, naturopaths, and fitness instructors know? *Eating Disorders*, *26*, 229-247. doi: 10.1080/10640266.2017.1397420

Appendix A: Published Candidacy Paper

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Not Quite This and Not Quite That: Anorexia Nervosa, Counselling Psychology, and Hermeneutic Inquiry in a Tapestry of Ambiguity

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Abstract

As a group of researchers exploring how to best understand the complex topic of families discovering their loved one has anorexia nervosa (AN), we found that we had to weave ambiguity into our design. Embracing ambiguity allowed us to create a tapestry that acknowledges the ambiguity of AN, counselling psychology (and other helping professions), and hermeneutic inquiry. In fact, the "not quite this and not quite that" features of these three constructs emerged as the thread that holds the inquiry together. We review the topic of AN through a lens of ambiguity. Further, we position both the field of counselling psychology and the research method of hermeneutic inquiry as compatible frameworks in the study of AN, in both practice and research. By acknowledging, and at times even embracing, ambiguity, we respect the complexity of the situation we are studying.

Keywords

Ambiguity, anorexia nervosa, hermeneutic inquiry, counselling psychology

Discovery is an objective of research and practice. This is also true of us; as authors, we are in the process of discovery. We seek to reveal, unveil, un-conceal a topic that is unknown, making discovery challenging and ambiguous. Central to any process of discovery is the concept of *aletheia*, a Greek term describing some act of uncovering and opening pieces of understanding, at the expense of covering and closing others (Moules, 2002). The particulars of a topic are both

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In this paper, we offer the argument that ambiguity is not something to be feared or fixed, but instead allows researchers and practitioners, particularly those specializing in the treatment of anorexia nervosa (AN), to be as effective as possible. Our topic of inquiry, an examination of the experience of families discovering that their child has AN, does not sit comfortably in one place. It does not have a permanent home in prevention, treatment, psycho-education, or stigma management nor does it have a place with any single member of the family. Moreover, the discipline of psychology that we (first and second author) are from is commonly mistaken for something that it is not. The nature of counselling psychology is not recognized by many and is still in some ways (and maybe always) in development. In addition to the complexity of these factors, the research approach we will utilize is arguably difficult and abstract; hermeneutic inquiry attends to history, interrelatedness, dialogue, language, and the possibility that we will be forever changed from understanding our topic, while at the same time noting that our understanding can never be complete (Gadamer, 2013). As we explored a research topic that involved anorexia nervosa, counselling psychology, and hermeneutic inquiry, we came to understand that we needed to address the concept of ambiguity to better prepare for our research.

The solution to ambiguity is to not solve it. Ambiguity is part of the process of research and of being a practitioner, allowing us to better understand the topic or the person in front of us. This is especially true when ambiguity is deeply ingrained in our topic, field, and research method. By welcoming ambiguity into research and practice, we remain open to possibilities and differences and are able to attend to the complexities of the phenomenon.

Ambiguity

Ambiguity refers to understanding a concept, word, or expression in two or more ways (Merriam-Webster, n.d.). Ever changing, shifting, unknowing, wavering, ambiguity refers to a concept with more than one meaning, and more than one interpretation. First used in the 1500s, the Latin term *ambiguus coming from the term ambigere meaning "to dispute about, contend, debate" (Online Etymology Dictionary, n.d.),* is made up of the prefix *ambi* meaning "both" or undecided and *agere* meaning "to drive" (Merriam-Webster, n.d.).

Uncertainty, doubt, and hesitation are sewn together, closely stitched to the concept of ambiguity, all pointing to the tendency to wander, waver, and change. Ambiguous concepts are not of poorer quality nor better than concepts that have known truths or are easy to decipher, but rather lend themselves well to interpretation through multiple lenses, perspectives, and fields of inquiry.

Throughout the paper, we argue that ambiguity does not need to be solved. Ambiguity might have something to teach us; we can grow in our understanding and be changed by the process of creating space for ambiguity. Instead of running from, fighting against, or trying to solve ambiguity, we must welcome multiplicity and constant change as concepts that will lead to better understanding. First, we will describe AN and the mystery and inconsistency that surrounds the disclosure, recognition, diagnosis, treatment, and recovery processes. It is our intention that by synthesizing the literature, we illustrate the ambiguity and ambivalence inherent for individuals and families affected. Further, we will position our research question: *How might we understand the experiences of parents who have discovered they have a child living with anorexia nervosa?* (research question of first author's doctoral dissertation*)* as not having a home in one field or another; leaving us as researchers wondering how to proceed in grey areas rather than having a black and white forward moving path. Thus, as a research team preparing to embark on a novel, discovery mission, we needed to create space for the complexities and richness of experiences inherent within the topic before collecting data. This complexity and richness can be likened to a tightly woven tapestry, one made up of many strings of different understandings, experiences, perspectives, biases – essentially, a tapestry honouring ambiguity. Next, a discussion about counselling psychology within a Canadian context is provided. Within this discussion, the multiple interpretations of what this profession is and what counselling psychologists actually do are emphasized. Last, hermeneutic inquiry is introduced and described as a method that is not quite this, nor that, but rather a method that is comfortable working with topics that are in the in-between. Further, since understanding the history and tradition of a phenomenon is fundamental to hermeneutic inquiry, throughout the paper brief histories of topics will be offered.

Overall, we seek to weave the string of ambiguity throughout each section and also call attention to the spaces in between the stitches, illustrating and sewing together the ambiguity and unknown in various fields. Together, this stitch work contributes to the larger tapestry, acknowledging ambiguity as a resource for research and practice. By highlighting the ambiguous thread throughout, we are creating space for the ambiguity, creating space for the uncertainty inherent in all areas. We do so not to suggest we solve this, but rather accept all areas as not quite this and not quite that and allow ourselves to explore and understand the uncertainty rather than avoid it. Evidently, our research process is a discovery, the same way that the topic is discovered.

Ambiguity and Anorexia Nervosa

The overall experience of having AN is marked with nuances, nebulosity, and ambivalence (Ryan & Callaghan, 2014; Williams & Reid, 2010). Weaving in and out of grey areas is cause for concern for many practitioners providing treatment to individuals with AN (Adlam, 2015; George, Thornton, Touyz, Waller, & Beumont, 2004) and is troublesome for those in support and caregiver roles, including family members and friends (Craigie, Hope, Tan, Stewart, & McMillan, 2013; Voriadaki, Simic, Espie, & Eisler, 2015). Evidently, ambiguity is not solely felt by the individual with AN, but also takes up space in the lives of professional helpers, care givers, and families. The ambiguous nature of AN will be illustrated through a

discussion of a) the history of AN; b) the ambivalence often reported towards AN; c) when the disorder is somehow discovered; d) the complicated recognition process, and e) the inconsistent outcomes for those with AN. At all points throughout the course of AN, ambiguity is not far away, it is not separate from the experience but rather a part of it.

History of Anorexia: The Hysterical Female

We begin with a brief history of AN, the first eating syndrome to be described by physicians in the 1870s (Gull, 1874; Lasèque, 1873). Broken down, the prefix *an* translates to "without" and *orexis* means "appetite," therefore in full translating into "lack of appetite" (Merriam-Webster, n.d.). The history of the conceptualization of AN is full of fascination and allure specific to the era, adding obscurity to the term's construction by medical professionals of the last several centuries. Researchers examining the archives of hospitals and mental asylums from the 16th to 19th centuries established notable accounts of fasting women and varied explanations of the disorder (Habermas, 2015; Parry-Jones, 1985).

The varied conceptualizations seem to be due to nationality and era. French physician, Lasègue, introduced the term *anorexie hystérique* in 1873, then one year later the term *anorexia nervosa* was coined by British physician, Gull, in 1874 (Habermas, 2015). Differences in conceptualizations stemmed from the French tradition of paying greater attention to psychological aspects of the condition, whereas British traditions emphasized the physical and behavioural features (Habermas, 2015).

French conceptualization. French physician, Lasègue described the condition in terms of hysteria, noting that his female patients had afflictions of the mind, suffering from "some emotion which she avows or conceals" (1873/1997, p. 493). Lasègue described the syndrome eventually becoming the sole object of preoccupation and portrayed his patients with AN as hysterical:

> what dominates in the mental condition of the hysterical patient is, above all, the state of quietude-I might almost say a condition of contentment truly pathological. Not only does she not sigh for recovery, but she is not ill-pleased with her condition, notwithstanding all the unpleasantness it is attended with. In comparing this satisfied assurance to the obstinacy of the insane, I do not think I am going too far. (p. 495)

British conceptualization. In 1874 (adapted and reprinted in 1997), Gull published a piece on a peculiar condition characterized by extreme emaciation, which he referred to a disease that occurred mostly in young females. Gull used phrases such as "complete anorexia for animal food, and almost complete anorexia for everything else" (p. 498) in his description of a former patient. In addition to describing his patients' physical states in his case studies, Gull made bold remarks regarding the treatment and lack of consideration of the patient's desires in her treatment. He made clear the dangers of continued starvation and noted that "the inclination of the patient must be in no way consulted" (p. 500). Further, Gull spoke to the destructive mental states of the women he treated, referring to young females being "specifically obnoxious to mental perversity" (p. 501) and females with this syndrome not being of sound mind to make their own choices about caloric consumption.

Since the time of these physicians' early writings of AN, others have gone beyond descriptions of lack of appetite and hysteria by describing distinctive features such as addiction to extreme thinness, referred to as a "drive towards emaciation" (Selvini Palazzoli, 1963/1974), and relentless pursuits of thinness (Bruch, 1965). Clearly, the evolution of these descriptors throughout the 19th and 20th century point to how AN has been disputed throughout history, and how many of these disputes continue in present among medical and mental health professionals.

Our understanding of AN has evolved over time. As more is understood about the development and trajectory of AN, the conceptualization will be modified to meet the time period and be congruent with modern practices and theory. Regardless of this changing and ambiguous identification process for what constitutes AN, questions still remain: What happens next for someone with AN? How do they experience AN?

Ambivalence to One's Experiences of Anorexia Nervosa

Not only is the history of AN marked with contestation, but so is the experience of living with the disorder including one's will to recover and autonomous motivations regarding AN (Nordbø, Espeset, Gulliksen, Skårderud, Geller, & Holte, 2012). Anorexia nervosa is considered to involve greater ambiguity and ambivalence compared to other eating disorders (e.g., bulimia nervosa, binge eating disorder), and individuals with AN tend to appreciate their symptoms differently than other groups experiencing mental illness (Nordbø, Espeset, Gulliksen, Skårderud, & Holte, 2006). Ego-syntonicity, referring to states, thoughts, behaviours, or feelings that are congruent with one's self-concept, and ambivalence are central features of AN (Marzola, Abbate-Daga, Gramaglia, Amianto, & Fassino, 2015). According to qualitative inquiries, some individuals have little desire to make changes, as AN is a source of pride and endurance providing a sense of achievement and self-confidence (Nordbø et al., 2006; Robinson, Kukucska, Guidetti, & Leavey, 2015). Further, researchers have illustrated how individuals with AN often depict their AN as providing them with a sense of security and stability, a way to avoid negative experiences, and as a way of obtaining a sense of power and inner sense of mastery and strength (Nordbø et al., 2006). At the same time, there are also individuals who are ambivalent about the disorder, not sure whether the AN controls them or whether they are in control of it, and irresolute if they wish to recover or maintain it (Colton & Pistrang, 2004; Reid, Burr, Williams, & Hammersley, 2008; Williams & Reid, 2010). Some individuals with AN regard their symptoms as a set of behaviours that are meaningful and positive in their lives (Nordbø et al., 2006), whereas others are ambivalent, only at times wishing to rid themselves of their restrictive eating behaviours and/or weight loss routines and resume the life they once lived (Williams & Reid, 2010). Much like the ambivalence regarding one's feelings toward their AN, individuals also vary in how they wish to proceed in the course of their experience with AN. Some may decide to disclose and ask for help, whereas others might not. Evidently, the experience of AN is individual and widely varied and, as such, an ambiguous quality emerges.

Disclosure of Anorexia Nervosa

Intentional and planned disclosure is the process of letting one's self be known to others (Corrigan & Rao, 2012). Individuals with AN may intentionally come forward, verbally sharing information about their eating and weight related behaviours. However, it is also possible that disclosures happen against the will of the person with AN (i.e., those who are caught purging). Being caught is not the same as making a willful decision to share intimate details with others. Conversely, people close to the person with AN may begin to suspect ill health and perhaps disordered eating when the size of an individual's body begins to unquestionably decrease or uncharacteristic eating and exercise habits are exhibited. Individuals communicating online via websites specifically created for those with eating disorders have reported feeling "too far gone" to continue concealing their illness from others (Williams, Russell-Mayhew, & Ireland, in press). This account supports a third type of disclosure, one that is neither intentional nor accidental, but rather an act of defeat, like one has lost their power over the eating disorder.

Individuals struggling with AN are often hesitant to disclose they have a problem (Becker et al., 1999). Researchers have suggested that disclosing one has an eating disorder is a gateway

for receiving professional help (Gilbert et al., 2012), however, it is more complex since the process of disclosure is characterized by ambiguity, for all parties involved. Disclosure unfolds over time (Williams et al., in press), opening up the possibility that it can resemble an entirely unique experience for everyone who discloses AN, and for everyone who is on the receiving end of that disclosure. Hence, perhaps a better term for this disclosure process is *discovery*, meaning to "obtain sight or knowledge of for the first time" (Merriam-Webster, n.d.). *Discover* was first used in the 1300s and meant to "divulge, reveal, disclose" (Online Etymology Dictionary, n.d.). From the Old French term *descovrir* meaning to "uncover, unroof, unveil, reveal, betray," and from the Late Latin *discooperire*, *dis-* meaning "opposite of" and *-cooperire* meaning "to cover up," the term conveys an undertone of betrayal or malicious exposure. In the 1550s, discoverer originally meant "informant" (Online Etymology Dictionary, n.d.), thus the etymology of the word maps well to the experience of one's AN being discovered by others, whether this was intentional or not.

Ambiguity of AN Recognition

After a discovery, sometimes a long, complicated, and ambiguous process of recognition and assessment follows. Factors contributing to this process include differentiating between other medical conditions and symptoms mimicking malnourishment (Schwarz, Ponder, & Feller, 2009), late-onset eating disorders (Santonastaso, Camporese, Caregaro, & Favaro, 2008), and atypical cases (American Psychiatric Association, 2013; Forney, Brown, Holland-Carter, Kennedy, & Keel, 2017). Recognition can be made challenging and go unnoticed for a number of reasons including unintentional denial, comprised of the individual with AN having impaired self-awareness and reality distortions (Vandereycken & Van Humbeeck, 2008). There may also be deliberate denial about symptoms and minimization that anything is wrong, which may occur as an expression of avoidance and fear of the consequences (Gray, Murray, & Eddy, 2015; Vandereycken & Van Humbeeck, 2008). Some practitioners go as far as to say that those with AN do not wish to be diagnosed or have their AN be recognized, because they do not wish to be treated (Adlam, 2015; Cooper, 2005; Halmi, 2005). Based on physicality alone, the prototypic individual with AN presents as malnourished and emaciated (Gray et al., 2015), yet just because there is a prototypic patient does not make the recognition of AN any easier as there can be multiple reasons for weight loss. Also adding to the ambiguous nature of recognition or assessment is that the behaviours and thoughts of someone with AN fall along the same spectrum of behaviours and thoughts that the majority of Western females have, that is a preoccupation with shape and weight (Tantleff-Dunn, Barnes, & Larose, 2011).

Various practitioners including Brown and Jasper (1993), Neumark-Sztainer, Levine, Paxton, Smolak, Piran, and Wertheim (2006), Russell-Mayhew (2007), and Sundgot-Borgen and Torstveit, (2010) have argued for a continuum of weight and body preoccupation. Brown and Jasper (1993) proposed that it was not accurate to stigmatize AN as "individual pathologies or diseases, at the same time we approve, even praise, the behaviour of those women who exercise and diet to attain the culturally prescribed body ideal" (p. 54). Brown and Jasper (1993) offered that it is difficult to suggest that someone who meets the diagnostic criteria of AN is any more pathological than someone who diets and engages in a rigid exercise routine for the purpose of controlling shape and weight. Feeling negatively towards one's body is a similar experience for women engaging in eating disorders and those dieting, as women internalize the ideal body image, recognizing that how they look will reflect how they are valued and treated (Brown & Jasper, 1993; Malson & Burns, 2009). A wide range of eating and weight related issues exist on a spectrum, ranging from negative body image and shape concerns to significantly distressing

eating disorders such as AN and bulimia nervosa (Levine & Smolak, 2006; Neumark-Sztainer, 2005; Russell-Mayhew, 2007). In this vein then, the ambiguity presents itself when behaviours that are considered normal, even virtuous, go too far.

Often, individuals with AN report a sense of self-confidence and feelings of worthiness after they have lost weight (Nordbø et al., 2006). In addition, individuals reported receiving positive feedback from others related to their shape and weight upon initially losing weight (Nordbø et al., 2006). Therefore, it is not surprising that these same individuals would experience tensions between the way they feel in their bodies after having lost weight and others conveying that they are concerned for them. Hence, the ambiguity must be endured by both the individuals with AN and the practitioners who are tasked with recognition. Apparently not everyone in these situations share the same perspectives and at times might be in direct tension with the other (Vandereycken & Van Humbeeck, 2008). Hence, the string of ambiguity continues to weave through, for both individuals experiencing AN and practitioners involved. There are multiple perspectives and positions in recognizing AN, emphasizing how this process in not black or white. Clear cut ways of recognizing that one is experiencing AN are not available; we must honour the ambiguity and hold space for all these positions so the tension and contestation are visible.

Anorexia Nervosa Outcome Variability

Treatment outcomes for AN are inconsistent, and of limited success for select individuals (Steinhausen, 2008). Though treatment for AN often temporarily succeeds in weight restoration, these individuals are considered to be at high risk for early relapse (Carter et al., 2012; Khalsa et al., 2017). The limited success in treating AN is not the fault of individuals with AN, rather perhaps an issue of not having yet found a treatment that works well for all. According to the most exhaustive reviews of treatment outcomes of AN to date, among surviving patients 37% reach full recovery within four years after the disorder onset, 33% improved, and 20-25% developed a chronic course of AN (Berkman, Lohr, & Bulik, 2007; Steinhausen, 2002). The crude mortality rate is reportedly 5-9%, which is accounted for by suicide or medical complications from starvation or compensatory behaviours (Berkman et al., 2007; Steinhausen, 2002). Thus, according to our knowledge of the course of AN, particularly the course following treatment, reaching the recovery status is not cut and dry.

The sense that one has to balance or somehow operate in ambiguous territory is not unique to those with AN, their family members, or those professionally working with this group. Experiencing uncertainty or multiple ways to go about something is also inherent in various practicing professions. One of these fields is counselling psychology, where multiplicity is the norm, creating space for ambiguity to flourish. As we move throughout this process of discovery, we intend to illustrate our position and entrance into this topic by framing it in terms of the ambiguity we, and other professionals face as we work and study with those with AN, but also the ambiguity that will be inherent in our practice because of our background. By doing so, we will illustrate using counselling psychology as an exemplar that there is another shade of grey, another realm of uncertainty, and another uneven stitch of the string of ambiguity.

We can identify that ambiguity is involved in both AN and counselling psychology separately. We must also acknowledge that the entire process that comes between AN emerging and interacting with counselling psychology professionals is ambiguous and uncertain in itself. First, families go through an ambiguous process in determining how to respond to this discovery, who to seek help from, how to interact with other family members. Families seek out counselling psychologists likely in the hopes that their ambiguity will be resolved by the

counselling psychologist, only for an entirely new environment fraught with ambiguity to be presented to them. Yet, this ambiguity is necessary if we are to truly embrace and honour each individual seeking treatment. Families with children with AN seek out treatment (i.e., counselling psychologists) to avoid ambiguity, to get clear answers, to help their child get better, whereas counselling psychologists make space for ambiguity, because they do not strive to fix ambiguous states, rather they operate within them. The profession of counselling psychology is comprised of many fixtures, and this intricate make up of responsibilities – sometimes a mixture of not quite this nor that, and/or sometimes both this and that, certainly does not make ambiguity go away. Hence, one door to ambiguity closes when families choose to seek professional help within a particular discipline, only for a completely new door to ambiguity to open when this same family interacts with a counselling psychologist.

Ambiguity and Counselling Psychology

The contestations and uncertainty towards what exactly counselling psychology (CP) is has been well documented (Bedi et al., 2011; Bedi, Sinacore, & Chistiani, 2016). The fact that CP has been recognized in Canada as a specialized discipline within the field of applied psychology since 1987, yet only received a formal definition in 2009 speaks to the equivocality of the profession's apparent "distinctive identity" (Bedi et al., 2011, p. 128). It is no wonder that counselling psychologists face uncertainty when positioning their training and approach to psychology as different compared to other psychology specialties and maybe even other professions, as up until eight years ago counselling psychologists were not united in their understanding of what CP stood for and its philosophical frameworks. In order to better understand the complexity, it is helpful to trace the history of CP in a Canadian context, allowing us to review its evolution and multifaceted approach. During our discussion of CP, it may be helpful to think of the profession as comprised as *both this and that*, hovering in-between various specialties.

History of Counselling Psychology in Canada

To understand CP's emergence in Canada, one also has to be cognizant of the profession's status at the same time south of the border. In the United States, CP was recognized as a distinct discipline by the American Psychological Association in 1951 (Munley, Duncan, & McDonnel, 2004). Due to this history and early recognition, CP in the United States was and is firmly embedded within professional psychology and is better understood to be a distinct specialization. Counselling psychology in Canada on the other hand, emerged years later in the late 1980s and was pioneered by professionals who were trained as either professional counsellors or psychologists (Lalande, 2004). Given this later emergence, the history of CP in Canada is intertwined with professionals who would not be considered to be part of psychology disciplines or CP in the United States.

A field that initially narrowly focused on guidance and career counselling (Robertson & Borgen, 2016) has undergone a transformation where an applied psychology specialization emerged from the roots. The evolution of CP in Canada has certainly added to the ambiguity, leaving individuals wondering if counselling psychologists primarily assist individuals with softer life transitions (e.g., career transitions), rather than more serious concerns (e.g., eating disorders), or both. Eating disorders, and AN in particular, are considered anything but soft, therefore individuals wonder if a field traditionally focused in career and guidance has a place in the treatment of the most fatal mental illness (Arcelus, Mitchell, Wales, & Nielsen, 2011; Keel et al., 2003). This tension becomes especially obvious after reviewing the history of the field. Ultimately, CP struggles to find its home. The string of ambiguity continues to be finely stitched

throughout, as multiple interpretations and understandings of what CP is, act as the foundation of which the field is based.

Counselling Psychology and Anorexia Nervosa

Counselling psychologists offer a broad array of services to their communities and the world beyond. Counselling psychologists across Canada focus on client strengths. An emphasis is placed on (a) respecting diversity, (b) social justice for those who are marginalized, (c) mental wellness versus psychopathology, (d) psychoeducation, (e) assisting with successful transitions throughout life, and (f) applied research (Bedi et al., 2011). It is clear that CP holds elements that are not quite this and not quite that **and** both this and that. CP conceptualizes individuals in terms of wellness, however the same professionals may also diagnosis a client with a label indicating psychopathology (Bedi et al., 2011). This represents a tension within the field, one that is especially relevant to counselling psychologists working with individuals with AN. Dominant discourses about AN come from a psycho-medical model, suggesting AN is an internalized, traditionally female phenomenon (Botha, 2015). If a clinician working from this model assigned a diagnosis, critics would suggest that by doing so the individual being treated would carry around a stigmatizing label as pathological (Botha, 2015). While receiving a diagnosis of AN may lead to an individual being accepted into a specialized service, considered by some to be what that individual requires for medical reasons, other counselling psychologists may be conflicted in assigning this label as it contradicts working from a wellness perspective. These conflicts are important to consider when honoring the ambiguity in CP, as CP welcomes strength based conceptualizations, while also valuing assessment, diagnosis, and evidenced based treatment, all of which are linked to the medical model.

Thus, the tension is not solved, nor does it have to be. Rather, we must be aware of this contestation within the field (and other helping professions). When the theme of ambiguity runs so deep through a phenomenon and a field, it is necessary to find a way to welcome differences and multiple interpretations.

Ambiguity and Hermeneutics

Hermeneutic inquiry, most simply put, is focused on interpreting phenomena and experience within the world. *Interpretation* refers to when a really or apparently unfamiliar meaning is made comprehensible (Grondin, 1994). Hermeneutic inquiry has been described as a "practice and theory of interpretation and understanding in human contexts" (Moules et al., 2015, p. 3). Rather than being driven by a rigid set of methodical rules dictating a pre-determined step-by-step method, hermeneutics offers a philosophy for understanding the world and is substantively driven (Moules et al., 2015). Described by Caputo (2015), hermeneutic inquiry does not apply principles or rules of understanding to cases, because this would imply that the topic and cases within it being studied are common and pre-determined. Rather, hermeneutics offers a way of proceeding in one's understanding by being led by the topic. Therefore, philosophical traditions cultivated over the last 2000 years guide hermeneutic research and practice.

Applying hermeneutics to applied practice is difficult to put one's finger on – it is not quite this and not quite that. For hermeneutic inquiry, this ambiguity and openness to possibilities is not considered a problem or a down fall of the approach to understanding, but rather this resistance to categorization is an asset (Moules et al., 2015). In the same sense that hermeneutics is difficult to categorize, there are not two people's experiences with AN that are the same. Though AN is a categorization of an eating disorder, the factors comprising one's experience of this disorder are infinite. The variance and ambiguity grows exponentially greater

in the recognition, disclosure, assessment, treatment, and recovery processes of AN. The feeling that one can never quite get a handle on AN parallels that of hermeneutics, as the topic of inquiry in hermeneutics is impossible to fully understand and see in its totality.

Hermeneutics requires a tolerance, even an embracing, of uncertainty, both of the topic and interpretation (Moules et al., 2015). To look for possible meanings and understandings of the topic requires one to oscillate within a world of uncertainty and mystery. This ambiguous oscillation parallels how practitioners working with and family members supporting those with AN must navigate their daily experiences – living in a world that is unknown to them, trying to do the best they can with little direction. As Gadamer noted, "the true locus of hermeneutics is this in-between" (2013, p. 306). Hermeneutics is not quite this and not quite that, as it is a philosophy and an applied practice.

Hermeneutic inquiry is capable of, and comfortable with studying something that may never be fully understood, and the same could be said of a practitioner working with, or a researcher studying one's experience of AN or a family's experience of discovering their child or sibling has AN. The concept of aletheia, the process of uncovering pieces of understanding, at the expense of closing others is very much alive in situations involving ambiguous topics. In order to be open to discovery, we must have the ability to encounter the other or the topic in a way that we acknowledge that our understanding is limited and in need of a reworking (Moules et al., 2015). Therefore, in order to discover this topic, and to do so with integrity, hermeneutic work:

> lies in its ability to hold tension, to be "not quite this and not quite that," in recognizing that with every opening, there is a closing of something else, in knowing that openings are invitations and portals to understanding, not dark rabbit holes where the topic disappears. (Moules et al., 2015, p. 179)

This quotation illustrates how we must honour the ambiguity inherent in the experience of having AN, and in a family's experience of discovering their loved one has AN. In order to discover, we must be flexible when encountering others' truths and accounts of the topic, and be open to the possibility that we may be changed in the process.

Creating Space for Ambiguity

Openness to ambiguity and not pushing it away may be uncomfortable, but when we are able to do this it could lead to better research and practice. It is natural to seek clear answers, as certainty helps with decisions about what to do next. Yet, we may take things for granted and act before considering all possibilities when something is clear-cut, and thought of as either this way or that way. When we take pieces of the situation for granted, we start to overlook details, narrowing our considerations for lessons and perspectives that might surprise us. Openness and the ability to work in the grey areas, creating space for different perspectives and different disciplines is advantageous. The solution to ambiguity is not to solve it, in fact, the solution is to do nothing to fix it or make it clear. Rather, in the spirit of aletheia, we must be open to the trade-off of concealing some pieces for the benefit of uncovering others, when discovering a topic, or understanding it more deeply.

Evidently, the experience of AN is marked with ambiguity. For adults, there is no best course of treatment for AN and certainly not a clear prognosis (Hubert Lacy & Sly, 2015; Steinhausen, 2008). Further, the recognition of AN adds more complexity; given that many females living in a Western society strive for the thin-ideal, there is a fine line between behaviour that is virtuous, or too far gone. Evidenced by the high mortality rate and inconsistent recovery statistics (Arcelus, Mitchell, Wales, & Nielsen, 2011; Berkman et al., 2007; Keel &

Brown, 2010), AN can be likened to an unevenly dispersed thread, a thread with variously spaced stitches, and even at times a stitch that appears to have stopped before it was expected. Interdisciplinary teams must be included in this fight, involving medical doctors, psychologists, social workers, nurses, nutritionists, dietitians, et cetera (American Psychiatric Association [APA], 2010). Though counselling psychologists would be ready to take up arms and use their holistic treatment approach, other professionals may question their place. Counselling psychologists are not limited to a specific type of inquiry, nor are bound to examining solely treatment related phenomenon. Further, the not quite this nor that placement of CP mirrors our research topic, as the study of a family's discovery that their child or sibling has AN is not quite considered treatment, nor prevention, or psychoeducation.

Given the ambiguity, hermeneutic inquiry is a great fit to study the uncertainty that is certain with AN and within the field of CP. Hermeneutics takes history and tradition of a topic into consideration, carefully trying to understand how the topic in its present form has evolved since its beginning. Further, the qualitative approach of hermeneutic inquiry is welcomed by counselling psychologists, who wish to discover the world and are open to multiple interpretations, not bound exclusively by quantitative methods. This openness to multiplicity and the possibility of one's perspective being changed in the process of understanding mirrors how practitioners must hold space for ambiguity. By holding space, not trying to solve for the ambiguity, we can learn from it and possibly grow.

Conclusion

An openness to working with the unknown is the key to working with individuals with AN. When discovering a topic, especially one marked by so many uncertainties and multiple interpretations, we must make a "hermeneutic wager" (Kearney, 2010) – taking a risk on an uncertain outcome, hoping we might better understand. In order to better understand the experiences of families discovering their child has AN and to learn more generally what it might be like for someone living with AN, we must be open to stepping into unknown territory and resist the urge to make our surroundings neater or more put together. By acknowledging the ambiguity inherent in one's experience of AN, we respect the complexity of the situation. By conceptualizing the many moving parts at play within this complex situation, as a tapestry of ambiguity, we reveal and hold space for interwoven complexities. By acknowledging, we are not solving for, nor are we tip toeing around it, but rather as we honour ambiguity, we come to accept that it is not quite this, nor that, and that is okay; perhaps it is even a resource.

References

Adlam, J. (2015). Refusal and coercion in the treatment of severe anorexia nervosa: The antigone paradigm. *Psychodynamic Practice*, *21*, 19-35. http://dx.doi.org/10.1080/14753634.2014.989714

Aletheia. (n.d.). *Online etymology dictionary*. Retrieved from http://www.etymonline.com/index.php?term=Alethea

Ambiguity. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriam-webster.com/dictionary/ambiguity

Ambiguous. (n.d.). *Online etymology dictionary*. Retrieved from http://www.etymonline.com/index.php?term=ambiguity

American Psychiatric Association [APA] (2010). *Practice guideline for the treatment of patients with eating disorders* (3rd ed.). Washington DC: Authors.

American Psychiatric Association [APA] (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Authors.

Anorexia. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriam-webster.com/dictionary/anorexia

Becker, A. E., Grinspoon, S. K., Kilbanski, A., & Herzog, D. B (1999). Eating disorders. *North England Journal of Medicine, 340*, 1092–1098. doi: 10.1056/NEJM199904083401407

Bedi, R. P., Haverkamp, B. E., Beatch, R., Cave, D. G., Domene, J. F., Harris, G. E., & Mikhail, A. M. (2011). Counselling psychology in a Canadian context: Definition and description. *Canadian Psychology/Psychologie canadienne*, *52*, 128. doi: 10.1037/a0023186

Bedi, R. P., Sinacore, A., & Christiani, K. D. (2016). Counselling psychology in Canada. *Counselling Psychology Quarterly*, *29*, 150-162, doi: 10.1080/09515070.2015.1128398

Berkman, N. D., Lohr, K. N., & Bulik, C. M. (2007). Outcomes of eating disorders: A systematic review of the literature. *International Journal of Eating Disorders*, *40*, 293-309. doi: 10.1002/eat.203

Bezanson, L., Hopkins, S., & Neault, R. A. (2016). Career guidance and counselling in Canada: Still changing after all these years. *Canadian Journal of Counselling and Psychotherapy (Online)*, *50*, 219-239. Retrieved from http://search.proquest.com.ezproxy.lib.ucalgary.ca/docview/1810336129/fulltextPDF/E62712D97E2748EDPQ/1?accountid=9838

Botha, D. (2015). Anorexia nervosa: A fresh perspective. *Theory & Psychology*, *25*, 328-345. doi: 10.1177/0959354314566490

Brown, C., & Jasper, K. (Eds.). (1993). *Consuming passions: Feminist approaches to weight preoccupation and eating disorders*. Toronto, ON, Canada: Second Story Press.

Bruch, H. (1965). The psychiatric differential diagnosis of anorexia nervosa. In J. E. Meyer & H. Feldman (Eds.)., *Anorexia nervosa* (pp. 70-87). Stuttgart: Thieme.

Canadian Psychological Association [CPA]. (n.d.). *Family Psychology*. Retrieved from http://www.cpa.ca/aboutcpa/cpasections/familypsychology/

Canadian Psychological Association [CPA]. (n.d.). Industrial/Organizational Psychology. Retrieved from http://www.cpa.ca/aboutcpa/cpasections/industrialorganizationalpsychology/

Caputo, J. D. (2015). Foreword: The wisdom of hermeneutics. In N.J. Moules, G. McCaffrey, J.C. Field, & C.M. Laing, *Conducting hermeneutic research: From philosophy to practice* (pp. ix- xiii). New York, NY: Peter Lang.

Carter, J. C., Mercer-Lynn, K. B., Norwood, S. J., Bewell-Weiss, C. V., Crosby, R. D., Woodside, D. B., & Olmsted, M. P. (2012). A prospective study of predictors of relapse in anorexia nervosa: Implications for relapse prevention. *Psychiatry Research*, *200*, 518-523. https://doi.org/10.1016/j.psychres.2012.04.037

Cash, T. F. (2002). The situational inventory of body-image dysphoria: Psychometric evidence and development of a short form. *International Journal of Eating Disorders*, 32, 362–366. doi: 10.1002/eat.10100

Craigie, J., Hope, T., Tan, J., Stewart, A., & McMillan, J. (2013). Agency, ambivalence and authenticity: The many ways in which anorexia nervosa can affect autonomy. *International Journal of Law in Context*, *9*, 20-36. doi:10.1017/S1744552312000456

Colton, A., & Pistrang, N. (2004). Adolescents' experiences of inpatient treatment for anorexia nervosa. *European Eating Disorders Review*, *12*, 307–316. doi: 10.1002/erv.587

Cooper, M. J. (2005) Cognitive theory in anorexia nervosa and bulimia nervosa: Progress, development and future directions. *Clinical Psychology Review*, 25, 511-531. doi:10.1016/j.cpr.2005.01.003

Corrigan, P., & Rao, D. (2012). On the self-stigma of mental illness: Stages, disclosure and strategies for change. *Canadian Journal of Psychiatry, 57*, 459-464. Retrieved from http://search.proquest.com.ezproxy.lib.ucalgary.ca/docview/1037989332/fulltextPDF/4F0702B5305E49E5PQ/1?accountid=9838

Discovery. (n.d.). *Merriam Webster's online dictionary*. Retrieved from https://www.merriam-webster.com/dictionary/discovery

Discover. (n.d.). *Online etymology dictionary*. Retrieved from http://www.etymonline.com/index.php?term=discover

Domene, J. F., & Bedi, R. P. (2013). Counseling and psychotherapy in Canada: Diversity and growth. In R. Moodley, U. P. Gielen, & R. Wu (Eds.), *Handbook of counseling and psychotherapy in an international context* (pp. 106-116). New York, NY: Routledge.

Forney, K. R., Brown, T. A., Holland-Carter, L. A., Kennedy, G. A., & Keel, P. K. (2017). Defining "significant weight loss" in atypical anorexia nervosa. *International Journal of Eating Disorders*, *50*, 952-962. doi: 10.1002/eat.22717

Franko, D. L., Keshaviah, A., Eddy, K. T., Krishna, M., Davis, M. C., Keel, P. K., & Herzog, D. B. (2013). A longitudinal investigation of mortality in anorexia nervosa and bulimia nervosa. *American Journal of Psychiatry*, *170*, 917-925. https://doi.org/10.1176/appi.ajp.2013.12070868

Gadamer, H-G. (2013). *Truth and method* (Bloomsbury revelations; J. Weinsheimer & D. G. Marshall, Trans.). London, UK: Bloomsbury.

George, L., Thornton, C., Touyz, S. W., Waller, G., & Beumont*, P. J. (2004). Motivational enhancement and schema-focused cognitive behaviour therapy in the treatment of chronic eating disorders. *Clinical Psychologist*, *8*, 81-85. doi: 10.1080/13284200412331304054

Gilbert, N., Arcelus, J., Cashmore, R., Thompson, B., Langham, C., & Meyer, C. (2012). Should I ask about eating? Patients' disclosure of eating disorder symptoms and help- seeking behaviour. *European Eating Disorders Review*, *20*, 80-85. doi:10.1002/erv.1143

Gladding, S. T., & Alderson, K. G. (2012). Counselling: A comprehensive profession (Éd. can.). Toronto, ON, Canada: Pearson Canada.

Gray, E. K., Murray, H. B., & Eddy, K. T. (2015). Diagnosing anorexia nervosa. In L. Smolak

& M. P. Levine (Eds.), *The Wiley handbook of eating disorders* (1st ed; pp. 93-104). West Sussex: John Wiley & Sons. doi: 10.1002/9781118574089.ch8

Grondin, J. (1994). *Introduction to philosophical hermeneutics*. New Haven, NY: Yale University Press.

Gull, W. W. (1997). V. – Anorexia nervosa (Apepsia Hysterica, Anorexia Hysterica). *Obesity*, *5*, 498-502. (Reprinted from *Transactions of the Clinical Society of London*, pp. 22-28, by W. W. Gull, 1874.) doi: 10.1002/j.1550-8528.1997.tb00677.x

Habermas, T. (2015). History of anorexia nervosa. In L. Smolak and M. P. Levine's (Eds.), *The Wiley handbook of eating disorders* (pp. 11-24*)*, West Sussex, UK: John Wiley & Sons.

Halmi, K. A. (2005). A complicated process: Diagnosing and treating anorexia nervosa and bulimia. *Psychiatric Times*, *22*, 59-59. Retrieved from http://go.galegroup.com.ezproxy.lib.ucalgary.ca/ps/i.do?p=HRCA&u=ucalgary&id=GALE|A132920473&v=2.1&it=r&sid=summon&authCount=1#

Hoek, H. W. (2006). Incidence, prevalence and mortality of anorexia nervosa and other eating disorders. *Current Opinion in Psychiatry*, *19*, 389-394. doi: 10.1097/01.yco.0000228759.95237.78

Hubert Lacey, J., & Sly, R. (2015). Severe and enduring anorexia nervosa: Diagnosis, features, and radical new treatment approaches. In L. Smolak & M. P. Levine's (Eds.), *The Wiley handbook of eating disorders* (pp. 142-156*)*, West Sussex, UK: John Wiley & Sons.

Kass, A. E., Kolko, R. P., & Wilfley, D. E. (2013). Psychological treatments for eating disorders. *Current Opinion in Psychiatry*, *26*, 549-555. doi:10.1097/YCO.0b013e328365a30e

Kearney, R. (2010). *Anatheism: Returning to god after god*. New York, NY: Columbia University Press. doi: 10.7312/kear14788

Keel, P. K., Dorer, D. J., Eddy, K. T., Franko, D., Charatan, D. L., & Herzog, D. B. (2003). Predictors of mortality in eating disorders. *Archives of General Psychiatry*, *60*, 179-183. doi: 10.1001/archpsyc.60.2.179

Keel, P. K., & Brown, T. A. (2010). Update on course and outcome in eating disorders. *International Journal of Eating Disorders*, 43, 195–204. doi: 10.1002/eat.20810

Khalsa, S. S., Portnoff, L. C., McCurdy-McKinnon, D., & Feusner, J. D. (2017). What happens after treatment? A systematic review of relapse, remission, and recovery in anorexia nervosa. *Journal of Eating Disorders*, *5*, 20. https://doi.org/10.1186/s40337-017-0145-3

Lalande, V. M. (2004). Counselling psychology: A Canadian perspective. *Counselling Psychology Quarterly*, *17*, 273-286. doi: http://dx.doi.org/10.1080/09515070412331317576

Lasègue, D. (1997). On hysterical anorexia. *Obesity*, *5*, 492-497. (Reprinted from *Medical Times*, pp. 265-266, by D. Lasègue, 1873.) doi: 10.1002/j.1550-8528.1997.tb00676.x

Levine, M. P., & Smolak, L. (2006). *The prevention of eating problems and eating disorders: Theory, research, and practice*. Mahwah, NJ: Lawrence Erlbaum

Malson, H., & Burns, M. (Eds.). (2009). *Critical feminist approaches to eating dis/orders*. New York, NY: Routledge.

Marzola, E., Abbate-Daga, G., Gramaglia, C., Amianto, F., & Fassino, S. (2015). A qualitative investigation into anorexia nervosa: The inner perspective. *Cogent Psychology*, *2*, 1032493. http://dx.doi.org/10.1080/23311908.2015.1032493

Moules, N. J. (2002). Hermeneutic inquiry: Paying heed to history and Hermes. An ancestral, substantive, and methodological tale. *International Journal of Qualitative Methods*, *1*, 1-21. Retrieved from http://journals.sagepub.com/doi/full/10.1177/160940690200100301

Moules, N. J., McCaffrey, G., Field, J. C., & Laing, C. M. (2015). *Conducting hermeneutic research: From philosophy to practice.* New York, NY: Peter Lang.

Munley, P. H., Duncan, L. E., & McDonnel, K. A. (2004). Counseling psychology in the United Sates of America. *Counselling Psychology Quarterly*, *17*, 247-271. doi: 10.1080/09515070412331317602

Neumark-Sztainer, D., Levine, M. P., Paxton, S. J., Smolak, L., Piran, N., & Wertheim, E. H. (2006). Prevention of body dissatisfaction and disordered eating: What next?. *Eating Disorders*, *14*, 265-285. doi: 10.1080/10640260600796184

Neumark-Sztainer, D. (2005). "*I'm, like, SO fat!": Helping your teen make healthy choices about eating and exercise in a weight-obsessed world*. New York, NY: Guilford.

Neumark-Sztainer, D., Story, M., Hannan, P. J., Perry, C. L., & Irving, L. M. (2002). Weight-related concerns and behaviors among overweight and non-overweight adolescents: Implications for preventing weight-related disorders. *Archives of Pediatrics and Adolescent Medicine*, *156*, 171–178. doi: 10.1001/archpedi.156.2.171

Nordbø, R. H. S., Espeset, E. M. S., Gulliksen, K. S., Skårderud, F., & Holte, A. (2006). The meaning of self-starvation: A qualitative study of patients' perception of anorexia nervosa. *The International Journal of Eating Disorders*, *39*, 556–564. doi: 10.1002/eat.20276

Nordbø, R. H., Espeset, E., Gulliksen, K. S., Skårderud, F., Geller, J., & Holte, A. (2012). Reluctance to recover in anorexia nervosa. *European Eating Disorders Review*, *20*, 60-67. doi: 10.1002/erv.1097

Reid, M., Burr, J., Williams, S., & Hammersley, R. (2008). Eating disorders patients' views on their disorders and on an outpatient service: A qualitative study. *Journal of Health Psychology*, *13*, 956–960. doi: 10.1177/1359105308095070

Robertson, S. E., & Borgen, W. A. (2016). Introduction to the special issue on the history of counselling in Canada. *Canadian Journal of Counselling & Psychotherapy/Revue Canadienne de Counseling et de Psychothérapie*, *50,* 197- 206. Retrieved from http://eds.b.ebscohost.com/abstract?site=eds&scope=site&jrnl=19236182&AN=117805418&h=Sa79M%2fo56PSq6d1KERKusemrWuUfmFMX%2bayYVYNQfZS0vU%2bHwNlhhRHJfELVSjiI8RwDmLa1gIteFoX4Sds7%2bg%3d%3d&crl=f&resultLocal=ErrCrlNoResults&resultNs=Ehost&crlhashurl=login.aspx%3fdirect%3dtrue%26profile%3dehost%26scope%3dsite%26authtype%3dcrawler%26jrnl%3d19236182%26AN%3d117805418

Robinson, P. H., Kukucska, R., Guidetti, G., & Leavey, G. (2015). Severe and enduring anorexia nervosa (SEED-AN): A qualitative study of patients with 20+ years of anorexia nervosa. *European Eating Disorders Review*, *23*, 318-326. doi: 10.1002/erv.2367

Russell-Mayhew, S. (2007). Preventing a continuum of disordered eating: Going beyond the individual. *The Prevention Researcher*, *14*, 7-10. Retrieved from http://www.onehealth.ca/r_alberta_nwt/video_conferences/E110404A-HOB.pdf

Ryan, C. J., & Callaghan, S. (2014). Treatment refusal in anorexia nervosa: The hardest of cases. *Journal of Bioethical Inquiry*, *11*, 43-45. doi: 10.1007/s11673-013-9498-8

Parry-Jones, W. L. L. (1985). Archival exploration of anorexia nervosa. *Journal of Psychiatric Research*, *19*, 95-100. doi: https://doi.org/10.1016/0022-3956(85)90004-4

Santonastaso, P., Camporese, A., Caregaro, L., & Favaro, A. (2008). Late onset anorexia nervosa treated with olanzapine: A case report. *Psychological Topics, 17*, 329-33. Retrieved from https://doaj.org/article/3c6564ab0cfe4060a2f5905e64e63fa9

Schwarz, D., Ponder, K. L., & Feller, E. R. (2009). Delayed diagnoses: Nonspecific findings and diagnostic challenges in eating disorders. *Case Reports in Medicine*. Article ID 841037 doi:10.1155/2009/841037

Selvini Palazzoli, M. (1974). *Anorexia nervosa*. London: Faber. (Original work published 1963).

Sinacore, A. L. (2015). Introduction. In A. L. Sinacore & F. Ginsberg (Eds.), *Canadian counselling and counselling psychology in the 21st century* (pp. 3-14). Montreal, QC, Canada: McGill-Queens University Press.

Steinhausen, H. C. (2002). The outcome of anorexia nervosa in the 20th century. *American Journal of Psychiatry*, *159*, 1284-1293. Retrieved from http://www.saegre.org.ar/biblioteca/arbol_bibliografico/agosto2005/1284_anorexia_outcome.pdf

Steinhausen, H. C. (2008). Outcome of eating disorders. *Child and Adolescent Psychiatric Clinics of North America*, *18*, 225-242. doi:10.1016/j.chc.2008.07.013

Sundgot-Borgen, J., & Torstveit, M. K. (2010). Aspects of disordered eating continuum in elite high-intensity sports. *Scandinavian Journal of Medicine & Science in Sports*, *20*, 112-121. doi: 10.1111/j.1600-0838.2010.01190.x

Tantleff-Dunn, S., Barnes, R. D., & Larose, J. G. (2011). It's not just a "woman thing": The current state of normative discontent. *Eating Disorders, 19*, 392-402. doi:10.1080/10640266.2011.609088

Vandereycken, W., & Van Humbeeck, I. (2008). Denial and concealment of eating disorders: A retrospective survey. *European Eating Disorders Review*, *16*, 109-114. doi: 10.1002/erv.857

von Ranson, K. M., Wallace, L. M., & Stevenson, A. (2012). Psychotherapies provided for eating disorders by community clinicians: Infrequent use of evidence-based treatment. *Psychotherapy Research*, 23, 333-343. doi:10.1080/10503307.2012.735377

Voriadaki, T., Simic, M., Espie, J., & Eisler, I. (2015). Intensive multi-family therapy for adolescent anorexia nervosa: Adolescents' and parents' day-to-day experiences. *Journal of Family Therapy*, *37*, 5-23. doi: 10.1111/1467-6427.12067

Watson, H. J., & Bulik, C. M. (2013). Update on the treatment of anorexia nervosa: Review of clinical trials, practice guidelines and emerging interventions. *Psychological Medicine*, *43*, 2477-2500. doi:10.1017/S0033291712002620

Williams, S., & Reid, M. (2010). Understanding the experience of ambivalence in anorexia nervosa: The maintainer's perspective. *Psychology and Health*, *25*, 551-567. doi: 10.1080/08870440802617629

Williams, E. P., Russell-Mayhew S., & Ireland, A. (in press). Disclosing an eating disorder: A situational analysis of online accounts. *The Qualitative Report*.

Young, R. (2009). Counseling in the Canadian mosaic: A cultural perspective. In. L. H. Gerstain, P. P. Heppner, K. L. Norworthy, S. Aegisdottir, & S. A. Leung (Eds.), *International handbook of cross-cultural counseling: Cultural assumptions and practices worldwide*. Thousand Oaks, CA: Sage.

Young, R. A., & Nichol, J. J. (2007). Counselling psychology in Canada: Advancing psychology for all. *Applied Psychology: An International Review*, *56*, 20-32. doi: 10.1111/j.1464-0597.2007.00273.x

Appendix B: Recruitment Poster

UNIVERSITY OF CALGARY

Title of Project: Parents Discovering their Child has Anorexia Nervosa

PARTICIPANTS NEEDED FOR RESEARCH

Purpose:

The purpose of this study is to better understand the experiences of parents who discover their child has anorexia nervosa (AN). Parents play a vital role in supporting children/adolescents/young adults with AN, yet little is known about how they come to discover their child is experiencing AN.

What you will be asked to do:

You would be asked to: complete a telephone screening interview (10-15 minutes). If you meet inclusion criteria, you will be invited to complete an in-person or telephone interview with the researcher (approximately 1 – 1.5 hours). You will be asked to discuss your experiences of discovering your child has/had AN.

In order to participate in this study, you must:

- be the parent of a child who experiences or used to experience AN;
- speak English;
- have had a child between the ages of 12 and 25 at the time/s of discovery;
- confirm your child is cared for by a physician, if child currently experiences AN.

Your parking will be reimbursed.

This study has been approved by the University of Calgary Conjoint Faculties Research Ethics Board

For more information about this study, or to volunteer for this study,
please contact:

Doctoral Student Researcher:
Emily Williams, MSc., Doctoral Candidate, Department of Educational Psychology
emily.williams@ucalgary.ca

Principal Investigator/Supervisor:
Shelly Russell-Mayhew, PhD., R. Psych., Department of Educational Psychology
mkrussel@ucalgary.ca

Appendix C: Unstructured Interview Guide

Sample interview questions:

Tell me about your experience of discovering your child has AN.

When you look back on your experience of discovery, what did you first notice, what would you go back and tell yourself?

How did you respond to the discovery?

How do you believe your response to the discovery impacted the person with AN?

Tell me whether you had concerns or suspicions that something was wrong prior to the discovery?

Since the discovery, have you ever wished you had done something differently?

Upon the discovery, what did you think about AN?

Tell me how your thoughts about your child and/or AN have changed or stayed the same since the discovery.

What would you like others to know about the discovery experience?

How would you describe other family members experienced the discovery?

Demographic questions:

What is your ethnicity?

How old are you?

How many children do you have?

If you are married/common law, how long you have been married/common law for?

If you are divorced/separated, how long you have been divorced/separated for?

If you are divorced/separated, how often is/are your child/children under your care?

Appendix D: Consent Form and Resources

Name of Researcher, Faculty, Department, Telephone & Email:

Emily Williams, MSc., Faculty of Graduate Studies, Werklund School of Education, (403) 919 7696, emily.williams@ucalgary.ca

Supervisor:

Shelly Russell-Mayhew, PhD., Professor, Werklund School of Education,
(403) 220 8375, mkrussel@ucalgary.ca

Title of Project:

Parents Discovering Their Child has Anorexia Nervosa: A Hermeneutic Inquiry

Sponsor:

Social Sciences and Research Humanities Council

This consent form, a copy of which has been given to you, is only part of the process of informed consent. If you want more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The University of Calgary Conjoint Faculties Research Ethics Board has approved this research study.

Purpose of the Study

The purpose of this study is to better understand the experiences of parents who discover their child has anorexia nervosa. Parents play a vital role in supporting children with anorexia nervosa, yet little is known about how they come to discover their child is experiencing anorexia nervosa. Given this knowledge gap, this study seeks to understand the lead up and eventual discovery that one's child has been experiencing anorexia nervosa, and how parents respond to such a discovery.

What Will I Be Asked To Do?

You will be invited to partake in a telephone screening interview. Information you provided during the screening interview will be retained and analyzed now that you are an interview participant. The researcher will lead the interview and gather information about potentially personal and sensitive information, including your discovery, responses at the time, reflections looking back at the discovery, and other details that will provide context for the experience. Interviews will be audio recorded.

Interviews will be 1 – 1.5 hours long and will take place over the phone or in person.

Participation in this study is completely voluntary. Consent may be withdrawn up until data analysis begins (typically one month after the interview). If partway through the interview you wish to stop, your request will be honoured and the interview will end immediately. Should you request that data collected up until the point of withdraw be destroyed, it will not be used in the study. Otherwise data collected up to the point of withdraw will be used. Further, you may decline to answer any and/or all questions.

What Type of Personal Information Will Be Collected

Should you agree to participate, you will be asked to provide your first and last name, telephone number, and email address.

Data obtained during the screening interview will be retained and analyzed.

Interviews will be audio recorded and transcribed verbatim. Audio recordings and transcription may be shared with members of the researcher's supervisory committee and/or professional transcribers (professionals who have signed a confidentiality agreement).

Prior to starting interviews, you will be asked to choose a pseudonym for yourself. This name will be used in transcripts and quotations in final writing pieces in replacement of your actual name in order to protect your anonymity and confidentiality. The same process will be followed if you mention the name of your child with anorexia nervosa.

The pseudonym I choose for myself is: _____

The pseudonym I choose for my child is: _____

Are there Risks or Benefits if I Participate?

The degree of risk for this study is low, as the probability and magnitude of potential harm is unlikely. While unlikely, during interviews you may experience mild psychological distress when asked to recount the experience of discovering you have/had a child living with anorexia nervosa.

Should you become distressed during the interview, you are encouraged to let the researcher know. The researcher will ask if you wish to take a break or discontinue. A comprehensive list of national and community psychological resources for the city of Calgary, surrounding areas are included at the end of this consent form.

This research may also yield several benefits. You may benefit from sharing your personal discovery as a parent of a child experiencing anorexia nervosa. Further, participating in this study may be beneficial simply because it will offer you an opportunity to discuss eating disorders, anorexia nervosa in particular, and your beliefs and knowledge of this topic, hereby increasing your mental health literacy.

Parking expenses incurred during interviews will be reimbursed

What Happens to the Information I Provide?

Every precaution to ensure confidentiality will be taken. Audio and transcription files will be saved within password protected and encrypted files, on a password protected computer. The researcher will keep all electronic files for five years and after that time all files will be deleted from the computer and hard drive.

Would you like to receive a summary of the study's results? Yes: ___ No: ___

If yes, please provide your contact information (e-mail address)

_____

Signatures

Your signature on this form indicates that 1) you understand to your satisfaction the information provided to you about your participation in this research project, and 2) you agree to participate in the research project.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant's Name: (please print) _____

Participant's Signature: _____ Date: _____

Researcher's Name: (please print) _____

Researcher's Signature: _____ Date: _____

Questions/Concerns

If you have any further questions or want clarification regarding this research and/or your participation, please contact:

Mrs. Emily Williams,
Werklund School of Education /Faculty of Graduate Studies
(403) 919 7696, emily.williams@ucalgary.ca

and Dr. Shelly Russell-Mayhew,
Werklund School of Education /Faculty of Graduate Studies,
(403) 220 8375, mkrussel@ucalgary.ca

If you have any concerns about the way you've been treated as a participant, please contact the Research Ethics Analyst, Research Services Office, University of Calgary at (403) 220-6289/220-4283; email cfreb@ucalgary.ca. A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form.

Community Mental Health Resources

Distress/Crisis and Counselling Resources in Calgary	
Emergency Services	Dial 911
Distress Centre Calgary Description: Free 24/7 phone service, offering service in 200 languages.	Telephone: (403) 266-4357 Website: http://www.distresscentre.com/
Mobile Response Team, Alberta Health Services Description: Provides mobile mental health services including crisis intervention, urgent psychiatric assessments, trauma responses, et cetera.	Access this service by calling the Distress Centre (403) 266-4357
Community Resource Team, Wood's Homes Description: 24/7 crisis support for families and children, in home or community visits, et cetera.	Telephone: (403) 299-9699 or 1-800-563-6106 Text: (587) 315-5000
Calgary Counselling Centre Description: Counselling services for individuals, couples, and families on a sliding fee scale.	Telephone: (403) 691-5991 Website: https://calgarycounselling.com/
Catholic Family Services Description: Counselling services for individuals, couples, and families on a sliding fee scale. Accepts individuals of all faiths.	Telephone: (403) 233-2360 Email: intake@cfs-ab.org Website: https://www.cfs-ab.org/
Access Mental Health, Alberta Health Services (Calgary Zone) Description: Provides information, consultation and referral to individuals residing in Calgary who have addiction and/or mental health concerns.	Telephone: (403) 943-1500 or 1-844-943-1500 (toll free)
Eastside Family Centre, Walk-In Counselling Description: Provides free, single session, walk in counselling for individuals, couples, and families.	Telephone: (403) 299-9696 Website: https://www.woodshomes.ca/programs/eastside-family-centre/
Family physicians	Yellow pages
Psychiatrists	Yellow pages

Psychologists	Yellow pages

Eating Disorder Resources in Calgary	
Calgary Silver Linings Foundation Description: Works collaboratively to create a world-class residential eating disorder treatment centre in Alberta.	Website: https://www.silverliningsfoundation.ca/
Calgary Eating Disorder Program Description: Offers treatment for people diagnosed with an eating disorder such as anorexia nervosa, bulimia nervosa, and other specified feeding or eating disorder.	Website: https://www.albertahealthservices.ca/info/service.aspx?id=1018201

Distress/Crisis and Counselling Resources in Southern/Central Alberta	
Distress Line of Southwestern Alberta, Canadian Mental Health Association Description: Free 24/7 crisis phone support.	Telephone: 1-888-787-2880 or (403) 327-7905
Lethbridge Family Services Description: Provides individual, couples and family counselling, group counselling, educational presentations, training/workshops, personal growth groups and outreach.	Telephone: (403) 327-5724 Website: https://www.lfsfamily.ca/info/about.php
Vantage Community Services Walk-In Clinic (Red Deer) Description: Provides free, walk-in individual, couples and family counselling. No referral required.	Website: http://www.vantagecommunityservices.ca/programs-services/walk-in-clinic/

Eating Disorder Resources in Southern Alberta	
Eating Disorder Support Network of Alberta Description: Eating Disorder Support Network of Alberta provides information, guidance, a provincial voice, a community hub and support.	Website: http://edsna.ca/

National and International Eating Disorder Resources	
National Eating Disorder Information Centre Description: NEDIC focuses on awareness and the prevention of eating disorders, food and weight preoccupation, and disordered eating by promoting critical thinking skills and a healthy, balanced-lifestyle.	Website: http://nedic.ca/
National Eating Disorders Association	Website: www.nationaleatingdisorders.org

Description: NEDA supports individuals and families affected by eating disorders, and serves as a catalyst for prevention, cures and access to quality care.	
BEAT: Beat Eating Disorders Description: Provides support for anyone affected by eating disorders, giving individuals experiencing an eating disorder and their loved ones a place where they feel listened to, supported and empowered.	Website: www.beateatingdisorders.org.uk
National Association of Anorexia Nervosa and Associated Disorders Description: Works in the areas of support, awareness, advocacy, referral, education, and prevention of anorexia nervosa and other related disorders.	Website: http://www.anad.org/

National Distress/Crisis Resources	
Crisis Services Canada Description: nationally available, regionally delivered service to anyone thinking about or affected by suicide. CSPS is available 24/7, via toll-free phone, text or chat.	Telephone: 437-317-4488 1-833-456-4566 (Crisis Line) Website: www.crisisservicescanada.ca
First Nations and Inuit Hope for Wellness Help Line – 24/7 Hours Description: offers immediate help to all indigenous people across Canada.	Telephone: 1-855-242-3310
PRINCE EDWARD ISLAND	
Island Helpline Description: free, confidential emotional support and crisis intervention to Islanders of all ages.	Telephone: 1-800-218-2885 Website: https://www.theislandhelpline.com/
NOVA SCOTIA	
Mental Health Mobile Crisis Telephone Line Description: provides crisis intervention for children, youth and adults experiencing a mental health crisis or mental distress.	Telephone: 902-429-8167 or 1-888-429-8167(toll free).
NEW BRUNSWICK	
Chimo Helpline Description: provincial service which provides a free, confidential and bilingual crisis intervention service to all residents of New Brunswick.	Telephone: 1-800-667-5005 (Toll Free) 506-450-4357 (Crisis Line) Website: www.chimohelpline.ca
QUEBEC	
Suicide Action Montreal (SAM)	Telephone: 1-866-277-3553 (Toll Free)

Description: free, confidential, bilingual telephone support for residents of Montreal.	514-723-4000 (Crisis Line) Website: www.suicideactionmontreal.org/
Le Centre d'Aide 24/7 Description: 24/7 distress and crisis intervention services for Outaouais residents.	Telephone: 819-595-9999 Website: www.centredaide247.ca
Tel-Aide Outaouais (Quebec and Ontario) Description: Crisis telephone support, in French only.	Distress Line (Gatineau): 819-775-3223 Distress Line (Ottawa): 613-741-6433 Toll Free: 1-800-567-9699 Website: www.telaideoutaouais.ca
ONTARIO	
Distress Centres Toronto Description: A free telephone help-line for people experiencing emotional distress (including suicide), providing confidential and caring emotional support.	Telephone: 416-408-4357 Website: www.torontodistresscentre.com
Beendigen Inc (Talk 4 Healing) (Northern Ontario) Description: Offers services in English, Ojibway, Oji-Cree, and Cree.	Telephone: 1-855-554-HEAL (4325) Website: http://www.talk4healing.com/
MANITOBA	
Manitoba Farm, Rural & Northern Support Services Description: confidential and non-judgmental counselling for anyone who lives on a Manitoba farm, or in a rural or Northern community.	Telephone: 204-571-4180 Toll free: 1-866-367-3276 Website: www.supportline.ca
Manitoba Suicide Prevention & Support Line (24/7*)* Description: 24-hour, non-judgemental and confidential service.	Telephone: Toll free: 1-877-435-7170 (204) 784-4097 Website: www.reasontolive.ca
SASKATCHEWAN	
Regina Mobile Crisis Services Description: available to help you with any problem that you are having difficulty coping with.	Telephone: 306-525-5333 Website: http://www.mobilecrisis.ca/mobile-crisis-helpline/
West Central Crisis and Family Support Centre (Central Saskatchewan) Description: provide support services to individuals and families experiencing violence and crisis in their lives, as well as outreach programs to communities within our boundaries.	Telephone: 306-463-6655 Mon - Fri 9 am - noon, 1 pm - 5 pm After hours: 306-933-6200 Website: http://westcentralcrisis.ca/

North East Outreach - Crisis Line Description: Telephone support in any crisis, supportive listening, and information and referrals.	Telephone: 1-800-611-6349 Website: http://northeastoutreach.ca/services/
BRITISH COLUMBIA	
Mental Health Support Line (BC-wide) Description: telephone services free to all BC residents.	**Telephone:** 310-6789 (no area code required) website: www.crisislines.bc.ca
Vancouver Coastal Health Region – Vancouver, Richmond, North Shore, Sea to Sky Distress Services Description: offers free, confidential support and resources.	Telephone: 604-872-3311
Vancouver Island Crisis Line Description: provide short-term non-judgemental support, crisis intervention, information, and resources to the entire island, the islands of the Georgia Strait, and the mainland communities between Powell River and Rivers Inlet.	Telephone: **1-888-494-3888** **Text:** 250-800-3806 (Available from 6:00 pm to 10:00 pm Pacific Time, seven days a week.) Website: http://www.vicrisis.ca/
NORTH WEST TERRITORIES	
NWT Help Line Description: confidential support to residents of the Northwest Territories. The help line also has an option for follow-up calls.	Telephone: 867-767-9061 Website: https://www.hss.gov.nt.ca/en/services/nwt-help-line
YUKON	
Yukon Distress & Support Line Description: anonymous, confidential and non-judgemental volunteer-run phone line.	Telephone: 1-844-533-3030 **The line is offered toll-free, Yukon-wide, nightly from 7pm - Midnight**. Website: http://www.manyrivers.yk.ca/services/yukon-distress-support-line/
NUNAVUT	
Nunavut Kamatsiaqtut Helpline Description: Nunavut Kamatsiaqtut Help Line provides anonymous and confidential telephone counselling for northerners in crisis.	Distress Line: 876-979-3333, or 800-265-3333 Website: http://www.nunavuthelpline.ca/

Appendix E: Crisis Protocol

In the highly unlikely event that it is revealed that the child with anorexia nervosa is in immediate medical danger and is not under the care of a medical doctor, the researcher will support the parents in seeking medical intervention. The researcher will help the parent(s) in formulating a plan that may include the following services:

Services to be Accessed in Crisis	
Emergency Services	Dial 9-1-1
Emergency Room	Alberta Children's Hospital 2888 Shaganappi Trail NW, Calgary, AB T3B 6A8 Foothills Medical Centre 1403 29 St NW, Calgary, AB T2N 2T9 Rockyview General Hospital 7007 14 St SW, Calgary, AB T2V 1P9 Peter Lougheed Centre 3500 26 Ave NE, Calgary, AB T1Y 6J4 Sheldon M. Chumir Health Centre 1213 4 St SW, Calgary, AB T2R 0X7 South Health Campus 4448 Front St SE, Calgary, AB T3M 1M4 Airdrie Regional Health Centre 1509 Centre St SW, Calgary, AB T2G 2E6 Sundre Hospital and Care Centre 709 1 St NE, Sundre, AB T0M 1X0 High River General Hospital 560 9 Ave SW, High River, AB T1V 1B3 Oilfields General Hospital 717 Government Rd, Black Diamond, AB T0L 0H0
Consult a physician	Yellow Pages

Appendix F: Copyright Permission

From: Shelly Russell-Mayhew
Sent: Mon 2019-03-25 1:08 PM
To: Gina Dimitropoulos; Nancy Moules; Emily Williams

You have my permission as well as co-author!
Shelly

From: Gina Dimitropoulos
Sent: Monday, March 25, 2019 1:00:47 PM
To: Nancy Moules; Emily Williams; Shelly Russell-Mayhew
Subject: Re: Copyright permission

Same here! You have my permission.

Gina

From: Nancy Moules
Sent: Monday, March 25, 2019 12:47 PM
To: Emily Williams; Shelly Russell-Mayhew; Gina Dimitropoulos
Subject: Re: Copyright permission

By way of this email, you have my permission as a co-author and also JAH permission as the Editor

Nancy J Moules, RN, PhD

From: Emily Williams
Date: Monday, March 25, 2019 at 12:46 PM
To: Shelly Russell-Mayhew, Gina Dimitropoulos, Dr. Nancy Moules
Subject: Copyright permission

Hello everyone,

I am emailing to ask if I have your permission as my co-authors for the manuscript "Not Quite This and Not Quite That: Anorexia Nervosa, Counselling Psychology, and Hermeneutic Inquiry in a Tapestry of Ambiguity" to include this work in my dissertation? I'd like to include this as my Appendix A, as readers can learn more about the ambiguity involved in the discovery process, without me having to re-write it.

I have been in touch with CopyRight at the UofC and they informed that this is the first step in this process. Please let me know as soon as you can, as my next step is emailing the journal to seek permission (heads up Nancy).

Thank you everyone!
Emily