

Young Women's Experiences of Hospitalization for Anorexia Nervosa:  
A Narrative Study

by

Jessica Rose Cumming  
BA, University of Victoria, 2015

A Thesis Submitted in Partial Fulfillment  
of the Requirements for the Degree of

MASTER OF ARTS

in the Department of Educational Psychology and Leadership Studies

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## **Supervisory Committee**

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E. Anne Marshall (Department of Educational Psychology and Leadership Studies)  
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## Abstract

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Anorexia Nervosa (AN) is a serious psychiatric disorder marked by the refusal to maintain a healthy body weight and excessive fear of gaining weight or becoming fat. This eating disorder is most prevalent among young women. Most research on hospitalized AN patients has been quantitative, and the experiences and perspectives of young women struggling with AN are underrepresented in the literature. Using a social constructionist and relational cultural lens, the research question addressed in the current study was *What are AN participants' experiences of helpful and not helpful factors in hospitalized care that affect recovery, motivation, and subjective well-being?* The study used a narrative approach, where eight young women aged 17–25 were interviewed regarding their stories of being treated in general or paediatric wards for AN. A thematic analysis was conducted to identify salient themes in the research interviews. The young women identified factors grouped into six main theme clusters that either helped or hindered their recovery during their time in the hospital, including: Staff Knowledge and Training, Treatment Experiences, Identity, Negative Treatment Impact, Abandonment, and Relationships. Implications of the findings for research, theory, and practice are discussed.

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## Acknowledgments

This research would not have been possible without the generous contributions of the eight young women who bravely told their stories in the hopes of improving outcomes for future patients with AN. I feel incredibly privileged that you were willing to share your stories with me and I am so appreciative of your willingness to participate in my research.

Next, I would like to extend my deepest thanks to my supervisor, Dr. Anne Marshall, without whom I never would have discovered my passion for research or learned the skills required to conduct a project of this scale. Your support at every stage of the research process has been incredible and I cannot express how grateful I am for the hours of thoughtful work you contributed to this project. Your support has meant very much to me.

I would also like to thank Dr. Natalee Popadiuk for providing additional perspective and wisdom to the writing of this research. I appreciate your helpful feedback and support, which contributed greatly to the study.

I wish to thank my practicum supervisor, Melissa Ander, for inspiring me to focus my thesis on this topic, as well as the rest of the team at the Fraser South Eating Disorder Program for providing perspective and helping me refine my ideas around inpatient care for AN. The skills and knowledge I gained during my practicum were vital in shaping the tone of this project and providing an additional lens with which to view my participants' experiences.

Finally, I want to thank my amazing family—my parents and my sister—for your unwavering support throughout my graduate school journey. Without you, I would never have been able to fully dedicate myself to the process of writing this research and I cannot thank you enough.

## Chapter 1—Introduction

### Background

Anorexia Nervosa (AN) is the third most prevalent chronic illness in teenaged girls (Norris et al., 2013). The DSM-V (American Psychiatric Association, 2013) describes AN as marked by dietary restriction resulting in “significantly low weight” (p. 338) for age and height, intense fear of weight gain, and “undue influence of body weight or shape on self-evaluation” (p. 339). It is infamous for having the highest mortality of any mental disorder with rates ranging anywhere from 5.6–19% (Andersen, 2007; Schwartz et al., 2008; Carter et al., 2012). Most experts agree that outpatient treatment is best in most cases of AN because it tends to yield equally successful outcomes with less life disruption (Bezance & Holliday, 2013; Gowers et al., 2007; Rance, Moller, & Clarke, 2017) and that treatment providers should use inpatient treatment sparingly (Ramjan & Gill, 2012). Yet, inpatient treatment or *tertiary care* is also widely considered a necessary part of the treatment continuum (e.g., Geller, Goodrich, Chan, Cockell, & Srikameswaran, 2012; Olmsted et al., 2010). Researchers highlight the controversy surrounding inpatient care due to the possibility of adverse outcomes (Bulik, Berkman, Brownley, Sedway, & Lohr, 2007; Schlegl et al., 2016). Geller and colleagues (2001) warn that, in some cases, hospitalization destroys the therapeutic relationship. Ramjan and Gill’s (2012) participants experienced inpatient admission as traumatic, making them feel afraid, angry, depressed and confused. It is perhaps for these reasons that dropout from these programs is so staggeringly high at 20–51% (Olmsted et al., 2010) and that recovery rates following hospitalization remain low (Rance et al., 2017). Geller et al. (2002) suggest that when hospitalization is necessary, admissions should be short since “as medical acuity decreases, distress level increases. Due to the nature of eating disorders (EDs), the more distressed patients become, the more likely they

are to increase problematic behaviours that sabotage treatment” (p. 133). Conversely, however, Redgrave et al. (2015) note that discharging AN patients early, before they achieve full weight restoration, is associated with relapse.

While few experts would argue that there are cases where hospitalization for AN is medically necessary, actual criteria for *when* it is required are inconsistent among treatment programs (Norris et al., 2013; Schwartz, Mansbach, Marion, Katzman, & Forman, 2008). Robinson (2006) states that people with EDs should be hospitalized when they are in need of treatment that community programs cannot deliver or when their life is in danger from lack of nutrition, imbalanced electrolytes, or risk of suicide. Thus, a large number of questions remain regarding good practices for hospitalizing young women with AN.

### **Tertiary Care Programs in Canada**

Norris et al. (2013) surveyed inpatient programs for EDs across Canada and found that programs vary dramatically in a number of ways. Canadian programs differ in program leadership (e.g., in which department they are housed), budget, separation from adult treatment, and whether they treat those less than 12 years of age. In Canada, most hospitals base admission on heart rate rather than a cutoff weight. While all programs included standard physical care components, including medical stabilization and restoration of nutrition, the types of psychological treatment or counselling available are much less consistent across the country. Most programs used family-based therapy (FBT) and all included some cognitive behavioural therapy (CBT). Other approaches used included motivational interviewing, narrative therapy, interpersonal therapy, psychodynamic therapy, and multifamily group therapy. Regarding the re-feeding aspects of the programs, most programs provided specific meals and all provided meal support, using nasogastric-feeding tubes as needed. Research shows that when program staff feel

incompetent to handle ED patients' psychological symptoms, they often try to refer these patients elsewhere (Reid, Williams, & Burr, 2010). This pattern is likely to result in patients attending a variety of different programs throughout their treatment. Since Smith, Chouliara, and colleagues (2016) identify unpredictability as a major stressor for AN clients, achieving greater consistency among programs would not only achieve a higher standard of care, it could actually make the treatment environment less aversive for these clients.

### **Lack of Evidence**

Research on inpatient programs for AN is severely lacking, and this is especially true of research done with adolescent participants. Compared to adults with AN, the following results have been found with adolescents: higher effect size, lower dropout rate, shorter duration of hospitalization, higher rates of clinically significant change, and lower rates of deterioration (Schlegl et al., 2016). These findings suggest that treatment for adolescents may actually be more effective and therefore it is critical to determine what works well for this age group.

In the absence of supporting research, inpatient treatment guidelines from England's National Institute for Clinical Excellence are based on expert opinion (Bezance & Holliday, 2013). The American Psychiatric Association's practice guidelines for EDs states hospitalization decisions should be made on the grounds of psychiatric and behavioural factors; treatment providers should consider how drastically food intake has declined, weight loss despite best efforts in outpatient treatment, external stressors, and comorbid conditions that require hospitalization (e.g., self-harm, suicidal ideation; Vandereycken, 2003). Criteria for admission are left up to clinical judgment (Olmsted et al., 2010); however, there is an identified lack of ED-specific training among clinicians who are currently admitting and treating EDs (Reid et al., 2010). There is a lack of research on mealtime protocols that help patients gain weight and

support their recovery; this is particularly problematic given that mealtimes are a frequent site of conflict between ED patients and treatment providers (Long, Wallis, Leung, & Meyer, 2012). Research does not reflect the type of treatment community agencies are currently providing, nor does it address what clinicians identify as critical issues they face, such as the best approach to weight restoration, appropriate refeeding protocols, hospitalization criteria, and medical risk (Bulik et al., 2007). Evidence is missing regarding how to achieve lasting weight restoration, appropriate hospitalization criteria, when discharge is appropriate, what features of inpatient programs are responsible for changes in symptoms, and when hospitalization is more helpful than outpatient treatment (Bulik et al., 2007; Vandereycken, 2003). Perhaps most importantly, negative consequences of inpatient treatment have not been explored (Vandereycken, 2003).

The quantitative research that does exist suffers from small sample sizes and lack of control (Bezance & Holliday, 2013; Bulik et al., 2007; Olmsted et al., 2010). The type of information that could be useful, such as referral and wait time information, or baseline and comparison measurements of symptoms is not always collected when patients access inpatient treatment (Norris et al., 2013).

The best evidence that exists supports family treatment but there is little evidence even for that, and comparison with other approaches is rare (Bezance & Holliday, 2013). Outpatient treatment is favoured over inpatient treatment. Bulik et al. (2007) note that research has failed to identify any factors consistently related to positive or negative outcomes. Almost every inpatient program uses behavioural management strategies, and yet Attia and Walsh (2009) point out, “there are no adequately controlled trials comparing behavioural refeeding programs with less intensive treatments or with treatments based on other principles, such as the resolution of underlying psychological difficulties” (p. 501). Programs differ in their criteria for moving a

client from inpatient to outpatient day treatment (Robinson, 2006). Little research exists on clients' experiences after they are discharged from inpatient treatment (Olmsted et al., 2010). One consistently identified problem in existing research on tertiary care programs for adolescents with AN is an absence of the viewpoint of the patients themselves (Long et al., 2012; Vandereycken, 2003). Rance et al. (2017) identify that in existing studies, participants indicate dissatisfaction with treatment; thus, finding out what patients think about their treatment is essential for improving clinical outcomes (e.g., Bezance & Holliday, 2013; Reid, Burr, Williams & Hammersley, 2008; Smith, Chouliara, et al., 2016).

### **Research Question and the Present Study**

Relationships play a pivotal role in both the development of and recovery from AN. Trepal, Boie, and Kress (2012) note that disconnection from others and subsequent isolation fuel AN symptoms. While disconnection is an unavoidable part of relationships, relationship ruptures followed by failure to repair these ruptures results in emotional suppression, providing an ideal environment for AN to flourish (Trepal, Boie, & Kress, 2012). By contrast, supportive and mutually empathic relationships create a context in which healing from AN can occur (Tantillo, Saftner, & Hauenstein, 2013). The present study used a relational lens, informed by relational cultural theory (RCT; Jordan, 2017), to examine young women's stories of their hospitalization for AN and its role in their recovery from the illness.

The purpose of this current study was to address the omission of young female AN clients' perspectives about being hospitalized in general wards. The main research question was *What are AN participants' experiences of helpful and not helpful factors in hospitalized care that affect recovery, motivation, and subjective well-being?* To answer this question, I used a narrative approach to interview eight young women from three Canadian provinces who had

experienced hospitalization for AN. I asked them to tell their stories of being in the hospital, with a particular emphasis on factors that aided or inhibited their recovery. Participants shared reflections on features of the hospital setting, program structure, and their relationships with others that affected them before, during, and after their hospitalization.

AN is a serious mental illness that is particularly prevalent among young women. Although the perspective of young women with AN has been deemed essential by several researchers (e.g., Bezance & Holliday, 2013; Smith, Chouliara, et al., 2016), very few studies have explored these young women's views of the care they received in hospital, particularly the views of adolescents in general wards. This study aims to address this gap, providing young women a chance to share their stories of what was helpful and not helpful during their inpatient treatment, as well as their suggestions for how hospital care could be improved. Finally, I have a particular interest in improving the inpatient treatment of AN that began with my own hospitalization for AN during my adolescence. I have since worked in my role as a counsellor with many young women with AN, whose experiences in the hospital involved similar challenges to those I experienced.

### **Summary of Chapter 1**

In this study, I sought to address the omission of young AN patients' voices from the literature on hospitalization for AN by asking young women previously hospitalized for AN to share their reflections on the care they received in inpatient settings. The next chapter reviews a selection of academic articles that focus on the topic of this study, including an overview of underlying theoretical positions and a brief review of supportive and hindering factors in AN recovery in the inpatient context.

## Chapter 2—Review of Selected Literature

This chapter presents a review of selected literature on several topics informing this research. The first section outlines the theoretical frameworks that provided the foundation for this study, namely social constructionism (SC) and relational cultural theory (RCT). Next, I provide an overview of the existing literature on young women hospitalized with AN. This includes a general overview of the characteristics of this population, followed by what have previously been identified as supports and barriers for them.

### Theoretical Background

Two main theoretical frameworks guided this research project: social constructionism (SC) and relational cultural theory (RCT). These approaches influenced the manner in which I conceptualized the issues my study participants faced, as well as my choice of research methods and the subsequent data analysis and interpretation of the research findings. SC and RCT are briefly discussed below.

Social constructionism. Social Constructionism is a theoretical approach relevant to many fields but is found mainly in the psychological literature (Burr, 2003). It characterizes psychology's search for universal laws or principles that apply to all humans as a misguided one that fails to recognize the diversity of the human experience (Gergen, 2015). Gergen (2015) credits three independent movements within separate disciplines for the popularization of SC. These are Foucault's critique of empiricism, the post-structuralist movement within literary theory, and the social sciences' examination of how social processes dictate what is accepted as fact. SC's postmodern approach challenges the positivist or scientific paradigm (Burr, 2003; Gergen, 2011). Gergen (2015) describes how the view of knowledge as communally constructed contradicts the possibility of absolute truth upon which positivist science is based. Burr (2003)

explains how SC relates to the postmodernist movement, which involves rejecting the notion of a single objective truth in favour of the idea that there are various equally valid ways of looking at the world. The key ideas of SC include

- questioning anything that is automatically assumed about the world or the human condition,
- the influence of culture and history on the ways in which we make sense of our experience,
- the role of social interactions in developing our assumptions and ways of understanding, and
- the influence of social constructions on our actions and responses (Burr, 2003).

Essentially, SC argues that many of our taken-for-granted “truths” are, in fact, relatively recent social constructs that evolved in response to events in particular places and times (Burr, 2003). For example, Gergen (2015) asserts that western cultures typically stress the rational knowledge of individuals who are self-directed, moral, and agentic. He counters that things we accept as truth about the world—for example, our morals, scientific knowledge, what is subjective or objective—in fact derive from relationships through “culturally situated social processes” (p. 100). Interactions among human beings are the mechanism through which experiences are constructed (Burr, 2006).

Language is the primary vehicle by which socially constructed ideas are transmitted. Burr (2006) explains that common-sense explanations suggest language reflects the reality of the world we live in; in contrast, SC posits that language actually creates reality. Some languages contain ideas or concepts for which there is no translation in others, making these ideas impossible to conceptualize for non-speakers; for example, in the Ifaluk language, it is impossible to translate the word ‘emotion’ (Burr, 2006). According to Gergen (2015), the way the world is depicted depends on broadly accepted conventions of language. Burr (2006) distinguishes between the *structuralist* view of language and the *post-structuralist* view, which is the one embraced by SC theorists. Both theories agree that language structures our experience of the world and gives it meaning; however, structuralism posits that these

meanings are fixed, while post-structuralism argues language is dynamic and meanings are subject to constant change (Burr, 2006). From the SC viewpoint, rather than being a means to map out what exists, language is a tool for generating meaning (Burr, 2003; Gergen, 2011).

Another position SC argues against is that of *essential humanism*, which “assumes that there is an essence at the core of an individual which is unique, coherent and unchanging” (Burr, 2006, p. 27). Burr (2006) contests the idea that an individual has a fixed nature or essence; rather, she locates explanations for people’s behaviour in the social sphere. Each individual, she argues, has multiple selves that emerge in particular social and cultural contexts. A young woman, for example, may be an eldest daughter, a keen soccer player, a hip-hop music fan, and a science undergraduate student; she acts somewhat differently when inhabiting each of these roles. An important implication of this fluid identity concerns people’s power to change their lives. Burr (2006) explains:

If language is indeed the place where identities are built, maintained and challenged, then this also means that language is the crucible of change, both personal and social. A person may feel trapped, restricted or oppressed by his or her identity....Poststructuralist theory would see language as the major site where these identities could be challenged or changed (p. 26).

Thus, the SC viewpoint provides more space for individuals to change their lives, because it does not tie their actions to fixed unchanging truths, but to dynamic processes that are constantly unfolding.

As far as research is concerned, “the insistence of social constructionism upon the importance of social meaning of accounts and discourses often leads logically to the use of qualitative methods as the research tools of choice.” (Burr, 2003, p. 24). SC researchers often use discourse analysis methods, which in practice can be highly variable (Burr, 2003). Gergen (2015) asserts that, in the absence of an objective truth, the more important question of research becomes, *what are the implications and consequences of adopting a particular perspective?* To accept the knowledge put forth by a theory or

research project, we affirm the values inherent in its construction and therefore we must consider who benefits most from any version of the truth (Gergen, 2015). Gergen argues that, “This concern with consequences essentially eradicates the longstanding distinction between fact and value, between is and ought” (p. 101). According to SC, the self is constantly defined and redefined through conversation with others, and research is one avenue in which such conversations can take place (Gergen, 2011).

Relational cultural theory. Emerging from Jean Baker Miller’s (1976) *Toward a New Psychology of Women*, RCT explores the role of relationships in development. Originally placing particular emphasis on women, the theory has since broadened to be more widely applicable across genders, cultures, and other demographic variables (Jordan, 2017). The fundamental idea underlying RCT is that (women’s) relational development is not addressed in traditional developmental theories (Comstock et al., 2008; Jordan, 2017).

Jordan (2001) cautions that “when ‘female’ is defined in contrast to ‘male,’ women are often seen as deficient in important human (male) qualities” (p. 95). Jordan (2017) asserts that what societies terms women’s weaknesses—most notably the need for relationships—are actually strengths according to RCT. In traditional developmental models, she explains, relationships take on a secondary role, with the emphasis placed instead on the individual self. Subsequently, women are devalued for prioritizing affiliation, rather than independence or self-development, which have typically been prized as the height of maturity, while any admission of need constitutes a risk of being seen as immature or a failure (Jordan, 2017). As a result of this emphasis on the individual, Jordan (2017) argues, our social structures are set up for competition, with those who can compete most effectively earning the most esteemed places in society.

In RCT, Jordan (2017) explains, maturation is seen, not as a movement away from dependence but toward a more mature form of dependence. Jordan (2008) argues that women, and also men, grow through their connections with other people. She places particular emphasis on what she calls *growth fostering relationships*, which are characterized by feelings of zest, clarity about self and others, self-worth, creative productivity, and motivation toward further connection. Jordan (2017) explains, “In a growth-fostering relationship...both people are open to being touched, moved, and changed by each other” (p. 231). These relationships involve both *mutual empowerment* and *mutual empathy* (Jordan, 2008). Mutual empowerment refers to the idea that, while some relationships begin with a power imbalance (e.g., the relationship between a client and therapist), their ultimate goal is to empower the person in the less dominant position (Jordan, 2017). Thus, in growth fostering relationships, both people are changed for the better by participating in the relationship. In mutual empathy, two (or more) people are completely attuned and responsive to one another (Jordan, 2017).

The opposite of growth fostering relationships are *power-over relationships*, where one person forces change on another person or one person’s integrity is stifled through a threat of rejection or punishment (Jordan, 2017). Jordan argues that power differences necessarily result in disconnection. She acknowledges disconnection as an inevitable part of human relationships; it is how we handle them that determines their impact on overall wellbeing. It takes vulnerability to reconnect following a disconnection, since there is always a risk of rejection (Jordan, 2017). She maintains that if an acute disconnection is met with an invalidating, shaming, angry, or rejecting response, people turn to disconnection strategies, such as disguising their authentic needs, in order to survive. This leads to chronic disconnection and stress or what is termed *condemned isolation* (Jordan, 2017). For evidence of the severity of condemned isolation, Jordan (2017)

points to recent neurobiological research that shows physical pain and emotional pain are indistinguishable to the human brain. Jordan (2008) also notes that this can happen on a broader societal scale, where it is known as *marginalization*. In marginalization, dominant groups devalue the norms and values of non-dominant groups (Jordan, 2017).

Condemned isolation and marginalization result from feeling insignificant and underappreciated with little hope of changing one's situation (Jordan, 2017). This can be overcome, however. On the individual level, Jordan explains, an acknowledgement of when we have hurt someone promotes healing and safety. By handling acute disconnections in a way that strengthens relationships, she posits, we can gradually shift people's old expectations of harmful interactions. Thus, "limiting and negative relational images begin to shift so that where formerly a person might have experienced scorn or rejection, that person now begins to see the possibility of acceptance, empathy, even love" (Jordan, 2017, p. 241). In the case of marginalization, widespread cultural changes addressing power imbalances embedded in societal structures will be required if true healing is to occur (Jordan, 2017).

Identity is of central concern in both the onset of and recovery from AN for young women (e.g., Bravender et al., 2017; McNamara & Parsons, 2016; Williams et al., 2016). Relationships, too, are seen as a crucial facet of ED psychopathology, as well as contributing to healing (O'Shaughnessy et al., 2013; McNamara & Parsons, 2016). Therefore, SC's focus on the construction of identity and RCT's prioritization of relationships seem to make them particularly appropriate lenses for the present research. From these theoretical and explanatory perspectives, I now focus on some of the characteristics and contributing factors of AN.

## **Anorexia Nervosa and Young Women**

A recent review by Dahlgren, Wisting, & Rø (2017) estimates the lifetime prevalence of AN at 1.7–3.6% of the population. In Canada, this would translate into approximately 627 046–1 327 862 people affected (Statistics Canada, 2017). Flament et al. (2015) found the prevalence of AN was 0–0.4% among a sample of young women. They note that changes in diagnostic criteria from the DSM-IV to the DSM-V increased the prevalence of AN two-fold among Canadian youth and among young women specifically. Prior to these changes, many young women with symptoms suggestive of AN were placed into the category of *eating disorder not otherwise specified* due to the absence of amenorrhea, which has been dropped as a criterion in the DSM-V (Flament et al., 2015). The typical age of onset for AN is during adolescence (Williams, King, & Fox, 2016; Salzmänn-Erikson & Dahlén, 2017). Since the best hope for a full recovery from AN is within the first seven years following its onset (Conti, Rhodes, & Adams, 2016), determining what can be done to support AN clients during these early years is crucial. Unfortunately, relatively little is known about what determines the long-term prognosis of AN, and what research has been done on it yielded mixed results (Tasaka et al., 2017; Vall & Wade, 2015). Since this type of evidence is missing, guidelines for treating EDs are based on expert opinion—usually in a medical context (Bezance & Holliday, 2013; Norris et al., 2013). It is perhaps not surprising, then, that different guidelines contradict one another and result in a wide range of program features in practice (Bezance & Holliday, 2013; Schwartz et al., 2008).

Hospitalization of young women with AN. The rate of hospitalization for AN among Canadian females aged 10–19 was 11.7 per 100 000 in 2013, which represents a striking increase of 42% since 2006 (Bushnik, 2016). While Rance and colleagues (2017) stress that the first-line treatment for AN should be psychologically-focused outpatient treatment, most researchers agree

there are cases of AN where outpatient treatment is insufficient to address physical complications of the disorder (Geller et al., 2012; Olmsted et al., 2010; Norris et al., 2013). Although it is generally agreed that this occurs when physical complications of the disorder threaten clients' health, exact criteria for admission are highly variable (Norris et al., 2013). Schwartz et al. (2008) found hospitals reached little consensus regarding cutoff numbers for weight and vital signs, and about how a client's level of success in outpatient treatment impacted their eligibility for admission. Similarly, there is little agreement among inpatient programs regarding appropriate criteria for discharge (Norris et al., 2013). Evidence on the optimal rate of weight gain, and therefore the duration of stay is changing. While a weight gain rate of 0.5–1 kg per week has typically been seen as desirable (Wales et al., 2016), some researchers now recommended weight gain be achieved at the faster rate of 2 kg per week (Redgrave et al., 2015). Schwartz and colleagues (2008) report mean hospitalization durations of 11–17 days; however, they caution that the long-term effects of different lengths of stay and rates of weight restoration have yet to be investigated. Estimates of recovery rates following hospitalization for AN range from 48–91%, with heterogeneity in the definition of recovery accounting for the wide variability in these estimates (Khalsa, Portnoff, McCurdy-McKinnon, & Feusner, 2017).

Features of the in-hospital experience vary widely, along with admission and discharge practices. Length of stay, ways of increasing dietary intake, and practices such as mealtime limits vary dramatically between programs (Schwartz et al., 2008). Physicians are forced to rely on their particular program's policies, as well as their own medical judgment, to guide treatment (Schwartz et al., 2008). Unfortunately, ED treatment is frequently carried out by non-experts, who may have little experience on which to base treatment decisions (Smith, Chouliara et al., 2016; Reid et al., 2010). In order to best serve the young women presenting to inpatient

programs with AN, it is necessary for research to determine what practices can best support them so evidence-based guidelines can be developed and adopted.

Eight qualitative studies were identified in the literature that examined clients' perspectives on inpatient treatment for AN (Long et al., 2012; Pemberton & Fox, 2011; Ramjan & Gill, 2012; Salzmann-Erikson & Dahlén, 2017; Smith, Chouliara et al., 2016; Strand, Bulik, von Hausswolff-Juhlin, & Gustafsson, 2017; Van Ommen, Meerwijk, Kars, Van Elburg, & Van Meijel, 2009; Zugai, Stein-Parbury, & Roche, 2013); of these, just under half focused on adolescent or young adult (under age 30) participants (Long et al., 2012; Ramjan & Gill, 2012; Van Ommen et al., 2009). Some studies focused on very narrow aspects of treatment, such as mealtime protocols (Long et al., 2012), emotion management (Pemberton & Fox, 2013), or the role of nurses (Van Ommen et al., 2009; Zugai et al., 2013). With the exception of Ramjan and Gill's (2012) study, the research that has been conducted on hospitalization for AN focuses on specialized inpatient programs for AN. However, space in such programs is limited and patients who cannot get a bed in a specialist program are typically sent to general wards (Reid et al., 2010). Reid and colleagues (2010) found staff in these settings reported feeling ill-equipped to handle these patients but little is known about what effect this has on the clients' experience. The client perspective has been deemed important in previous research (Bezance & Holliday, 2013; Long et al., 2012; Zugai et al., 2013). Yet, research examining the overall experience of hospitalization on a general ward, from the perspective of young female hospitalized clients, is all but nonexistent. The present study aims to address this gap in the literature, in order to provide insight into AN clients' experiences and contribute to the improvement of hospitalization practices for this population.

## Supportive Factors

Despite the overall lack of research pertaining to adolescent tertiary care for AN, a few factors that increase the likelihood of positive outcomes have consistently emerged from the literature that does exist. These include non-professional support, therapeutic relationship, staff attitudes, staff knowledge, structure, autonomy/voice and individualization of treatment.

Non-professional support. Young women with AN report valuing support from non-professionals such as friends and family, as long as they are able to provide empathy and understand the clients' feelings (Tierney, 2008). The role of non-professional support for adolescents with AN in inpatient treatment can be divided into family support and peer support. Tierney's (2008) participants expressed mixed opinions of parental involvement. Many of them shared that having their parents and, in particular, their mothers involved in treatment was a key support in their recovery. However, not all parents are able to be supportive and, if parents are unable to communicate understanding to their daughters, their involvement can detract from recovery (McNamara & Parsons, 2016; Tierney, 2008). Van Ommen et al. (2009) noted that bringing parents in to observe a meal in the inpatient setting could be a useful strategy to increase the likelihood of consistency between the home and treatment environments. Bakker et al. (2011) emphasize that treatment providers should build good relationships with parents by exchanging detailed information and making plans for when the patient is allowed to leave the hospital both temporarily and permanently.

Contact with peers outside the hospital was identified as helpful by patients with AN (Bezance & Holliday, 2013). It is troubling to note that some programs prevented this, restricting visiting privileges to patients' families, while adolescent patients hospitalized for other conditions on the same ward were permitted any visitors they wanted (Ramjan & Gill, 2012).

Bakker and colleagues (2011) encourage re-engagement with age-appropriate social activities while AN patients are hospitalized, warning that cutting these adolescents off from their peers is not helpful. Because women with AN are prone to isolation in general (e.g., O'Shaughnessy, Dallos, & Gough, 2013; Tierney & Fox, 2010), there is a risk that they will become further isolated as inpatients due to separation from friends outside the hospital. Overall, contact with friends not struggling with AN is typically acknowledged as a positive influence and more opportunities could be made to encourage the maintenance of such relationships.

The impact of peers inside the hospital who were also struggling with AN is more mixed (Bezance & Holliday, 2013; Tierney, 2008). On the one hand, patients entering a hospital program depend on other ED patients for support, role modeling, and demonstrating examples of privileges they can earn (Bakker, van Meijel, Beukers, van Ommen, Meerwijk, & van Elburg, 2011; Van Ommen et al., 2009). Smith et al. (2016) found AN patients depend on other patients as examples of how to cope and for acceptance they cannot get elsewhere. One particularly desirable feature of connecting with others, according to participants, is the social aspect of meals; a key part of normalizing eating is reconnecting to the role of food in social contexts and modelling this in the hospital environment can be helpful (Bakker et al., 2011; Long et al., 2012). McNamara and Parsons (2016) note that cultivating a community of recovery can be a protective factor against relapse since the shared identity among these groups is a motivating factor.

On the other hand, Bezance and Holliday (2013) found that being around others with AN led to guilt, competition, comparison, and distress. Other authors identify problematic group dynamics in AN treatment settings, where patients feel jealous of one another and begin competing for who is the most ill (Olmsted et al., 2010; Smith et al., 2016; Vandereycken, 2011). Additionally, seeing others struggle can be a difficult emotional experience for patients with AN

(Smith et al., 2016; Vandereycken, 2011). Since Pemberton and Fox (2013) note that AN patients struggle with emotion and their typical response to cope with overwhelming emotions is to engage in ED behaviours, the upsetting influence of exposure to others with EDs could be damaging to their recovery.

Therapeutic relationship. Hospitalized AN patients value a strong therapeutic relationship, seeing it as crucial to their recovery (Rance et al., 2017). The ideal therapeutic relationship, according to these clients, is characterized by empathy, understanding, support, and a lack of judgment (Sheridan & McArdle, 2015; Van Ommen et al., 2009). Certain research findings suggest the therapeutic relationship may in fact be more important than treatment content (Smith, Chouliara, et al., 2016). AN patients want to feel connected and equal to their therapist (Tierney, 2008). Van Ommen et al. (2009) found that patients felt particularly close to certain nurses who were open, displayed expertise, and attempted to connect with them. Building trust is key, since Bakker et al. (2012) warn that this relationship can be strained as a result of distrust on either clients' or practitioners' part. A trusting and supportive relationship is likely to occur within individual therapy, but the availability and continuity of such therapists tend to be lacking in the hospital environment (Tierney, 2008). However, Salzmann-Erikson & Dahlén (2017) suggest that even quick interactions can be enough to display the type of compassion AN patients need to develop trust and that, over time, the accumulation of these brief positive experiences can be equal to or better than similar interactions in weekly therapy sessions.

The therapeutic relationship has been linked to desirable outcomes in AN treatment. Sheridan and McArdle found a strong therapeutic relationship was connected with engagement and reduced dropout. Similarly, Salzmann-Erikson and Dahlén found clients' views of the

therapeutic relationship could predict how fast the client would achieve weight restoration. Thus, making staff–client relationships a priority in the inpatient environment could contribute to symptom improvement, client motivation, and retention.

Staff attitude. Patients with AN consistently report that they need hospital staff to be sensitive to and understanding of their struggles (Bezance & Holliday, 2013; Geller, Williams, & Srikanth, 2001). Unfortunately, prejudices against people with AN can interfere with this (Geller et al., 2001). Sadly, Dimitropoulos and colleagues (2016) found treatment providers are not immune to such prejudices. Reas et al. (2017) explain that, even in today’s world, “individuals with eating disorders [are] viewed by society at large as attention-seeking, blameworthy, or as having a trivial self-imposed problem and viewed by professionals as vain, manipulative or difficult” (p. 22). For patients to feel respected and understood, staff must display attitudinal commitment, including accepting clients, being attentive, respecting clients, being empathic, showing interest, being honest, and validating clients’ negative experiences (Bakker et al., 2011). It is particularly crucial that they make it clear to patients that any conflict they may have is with the AN and not with the person (Bakker et al., 2011). One often-suggested strategy for staff to communicate this attitude to patients is for them to function as role models, eating with patients to help them feel more comfortable (Long et al., 2012; Ramjan & Gill, 2012; Van Ommen et al., 2009).

Staff knowledge. In addition to a general caring attitude, it is essential that hospital staff have specific knowledge and training related to EDs (e.g., Bezance & Holliday, 2013; Ramjan & Gill, 2012). Worryingly, this is frequently not the case (Bezance & Holliday, 2013; Pemberton & Fox, 2011; Smith, Chouliara et al., 2016). Doctors and other hospital staff are sometimes expected to treat EDs with no formal training at all and to learn all they need to know on the

job (Reid et al., 2010). It is unsurprising, then, that treatment providers frequently fall prey to the same myths about ED treatment that pervade society as a whole, something that could be remedied by formal training (Dimitropoulos, Freeman, Muskat, Domingo, & McCallum, 2016). Ramjan and Gill (2012) stress that more mental health training for nurses is essential, as well as training specific to AN. Staff report frustration with lack of training opportunities and feel uncertain about how to help patients with AN (Long et al., 2012).

Such lack of education may lead staff to think of AN patients synonymously with their illness, as opposed to considering the entire individual (Jenkins & Ogden, 2012; Ramjan & Gill, 2012; Sheridan & McArdle, 2015; Smith, Chouliara et al., 2016). This can lead to negative self-identification as “deviant” (Williams et al., 2016). Patients state that they depend on staff knowledge to help them make sense of their behaviour (Van Ommen et al., 2009). Additionally, some patients report a need for staff to understand the way their illness works because otherwise they are able to trick them and secretly engage in ED behaviours (Tierney, 2008; Van Ommen et al., 2009). These patients long to be understood by those caring for them on multiple levels, particularly concerning their cognitions and emotions but also the physical and behavioural correlates of their illness (Long et al., 2012). Thus, a focus on improving training opportunities for staff who work with AN inpatients is imperative for these young women’s wellbeing.

Structure. Many studies emphasize the need to be clear at the beginning of treatment about the rules for eating, and the need to entirely remove control from the client for the first part of their treatment (Bakker et al., 2011; Van Ommen et al., 2009; Vandereycken, 2003). Hospital staff must be explicit about their expectations for their clients and, if they see these are not met, they must start an open dialogue (Bakker et al., 2011). Creating a safe, structured environment is necessary at first so that hospitalized patients can slowly begin to let go of some of their rigidity

(Vandereycken, 2003). A certain level of normalization, structure, and control are seen as necessary for treatment success (Bezance & Holliday, 2013). Lack of structure and predictability in routine lead to anxiety for these clients, which can strengthen AN symptoms (Long et al., 2012; Pemberton & Fox, 2013; Smith, Chouliara et al., 2016). Additionally, having rules and structure imposed on AN patients enables them to let go of some of the guilt they associate with eating and avoiding exercise, since it is not their own choice (Tierney, 2008). Van Ommen et al. (2009) reported that patients initially found it very stressful to be thrown into group activities and be expected to follow the structured program right away, but later indicated it had been helpful.

While this high level of structure is useful in restoring clients' weight and normalizing eating patterns, it is also important that staff recognize clients' progress by gradually allowing them more responsibility (Ramjan & Gill, 2012; Van Ommen et al., 2009). Tierney (2008) points out that these patients do want to be challenged but, if they feel they are being judged, they will begin to resist. Ramjan and Gill (2012) warn that structure can also be detrimental to treatment if it is taken too far; in their study of adolescent AN patients in a general hospital ward, patients' bathroom use was rigidly controlled and all activities were strictly scheduled, while non-ED patients on the ward were afforded far more privileges and flexibility. AN patients experienced this as demeaning and found it detracted from the usefulness of treatment.

Autonomy and voice. Bezance and Holliday (2013) stress that it is vital for patients to have the opportunity to eventually take control over their own food and decisions during their time in treatment. They found that choice over one's care led to empowerment, a sense of responsibility, and a shift from a conflict between client and treatment provider to conflict between client and AN. Geller et al. (2001) believe clinicians should emphasize agency and try to come to a collaborative understanding. Long and co-authors (2012) conducted a study asking hospitalized

AN patients for their impressions of mealtimes in the hospital. These patients expressed a wish to be more actively involved in their treatment, including meal-planning, meal preparation decision-making, goal-setting, and learning skills that would be useful outside the hospital environment. Van Ommen et al. (2009) echo these sentiments, noting that, while it is necessary for staff to continue confronting and challenging clients, they should be afforded increasing opportunities to practice skills and solve their own problems with support. Sheridan and McArdle (2015) discuss the relationship between motivation and treatment outcome; these authors maintain that guidance, rather than coercion, is essential and treatment goals need to be mutually agreed-upon. Furthermore, they found that when patients had opportunities to learn, reflect, and develop emotionally and were given appropriate choices and responsibility, dropout from treatment was lower. Ross and Green (2011) conceive of inpatient treatment as a bridge to independence, as well as a context for discovery. Finally, Ramjan and Gill (2012) state that adolescent AN patients should have more control over decisions that affect their lives.

Individualization. A common critique of inpatient programs for AN is the high level of standardization with little room to tailor treatment to individuals (Ramjan & Gill, 2012; Vandereycken, 2003). Jenkins and Ogden (2012) note that rushing patients through treatment with little regard for their individual needs fails to recognize and honour the complexity of the struggle to recover from AN. Part of this needed individualization is about returning responsibility to the client as they are ready to make their own choices, to boost their confidence, with opportunities to build more structure back in if necessary (Bakker et al., 2011). As patients perceive they are progressing and are gradually given more opportunities to demonstrate competence, confidence and motivation increase (Sheridan & McArdle, 2015; Van Ommen et al., 2009). However, there are many other ways to tailor treatment and, when patients view

components of treatment as fun or interesting, intrinsic motivation increases (Sheridan & McArdle, 2015). AN is an illness that has strong impacts on identity, where the disorder becomes intertwined with clients' sense of self (e.g., Kendall, 2013; Tierney & Fox, 2010). This makes recognition of their individual qualities a vital part of helping them to overcome the disease. When staff treat all AN patients the same or as a collection of symptoms rather than a human being, the illness becomes more entrenched and recovery can seem impossible (Kendall, 2013; Malson et al., 2004; Rance et al., 2017). This circular process, Williams and colleagues (2016) caution, results in patients being labeled as "chronic" and seen as incapable of overcoming AN. For these reasons, Salzman-Erikson and Dahlén (2017) assert that rules and restrictions applied to AN patients should be relevant to their particular situation, and not universally prescribed to all ED clients.

### **Challenges**

Certain features of inpatient programs are detrimental to achieving treatment outcomes. These include power struggles, loss of identity or meaning, meal features, overemphasizing the physical, staff lack of understanding, competition, and transitions.

Power struggles. Many researchers have identified that treatment can become a struggle for control between staff and patients (Bezance & Holliday, 2013; Long et al., 2012; Vandereycken, 2003). Long et al. (2012) identify that mealtimes, in particular, may become a metaphorical battleground, pitting treatment providers against patients in a battle of wills. Their participants felt under constant observation from both staff and other patients and, if they expressed discomfort with this, staff minimized their feelings. Furthermore, these participants reported that low-quality food, bizarre food combinations, and limited choices made eating more difficult. The

role of distraction during meals is unclear; some participants find this helpful while others report it is counterproductive.

Geller et al. (2001) warn that scare tactics—trying to frighten patients into changing—are both ineffective and distressing; distress results in less behavioural change and a weak therapeutic relationship. Similarly, Sheridan and McArdle (2015) note that coercive treatment is ineffective; a nondirective approach resonates better with patients and, perhaps seeming to be counterintuitive, is connected to better emotional and behavioural outcomes. In Ramjan and Gill's (2012) disturbing study, both staff and patients reported experiencing the ward as a prison with patients feeling like prisoners and nurses feeling like wardens. These nurses felt they had to shut down or go on autopilot to cope with the stress of the job while patients felt punished for failure to comply and that their freedom was heavily restricted. Ramjan and Gill assert, “for all practical purposes, [these patients] were locked up, deprived of personal liberties and social contact until they gained weight” (2012, p. 31). In contrast with the warm empathic therapeutic relationship patients crave, this jailer–prisoner type of relationship breeds distrust and can cause both staff and patients to shut down (Ramjan & Gill, 2012).

Loss of identity and meaning. Part of successful treatment for AN is building or rebuilding a personal identity that exists outside of the ED (McNamara & Parsons, 2016; Tierney, 2008). Hospitalization can interfere with this treatment goal if it strengthens the anorexic identity to which patients have become attached (Vandereycken, 2003). Staff may inadvertently reinforce this by trivializing behaviours as “typical” of those with AN (Bezance & Holliday, 2013) or, in extreme cases, viewing their patients as cases instead of people (Tierney, 2008). Long et al. (2012) found many participants believed their views were ignored and they had no choices or autonomy, resulting in a loss of identity that translated into feeling disconnected or checked out

from program activities, particularly at mealtimes. Ramjan & Gill (2012) found their participants often felt bored in the hospital setting, lending support to Sheridan and McArdle's (2015) assertion that varied types of therapy are preferable to relieve patients from the constant symptom-talk and singular focus on the physical correlates of AN.

A related concern was that patients felt disconnected from the outside world and their previous lives. Attia and Walsh (2009) note, "as with any extended structured-treatment program, therapy for patients with anorexia nervosa is associated with interruptions in social, school, or work activities, as well as with feelings of powerlessness and a loss of control among patients" (p. 504). Similarly, Ramjan and Gill (2012) heard from their participants that being in the hospital felt like a time-out from real life. Bezance and Holliday's (2013) participants expressed desires to reconnect with their outside life, as well as with people and activities that were important to them. Having a treatment environment that is too far removed from what patients are accustomed to in their lives outside the hospital is problematic because the ultimate goal is for them to return to that outside environment and be able to manage their illness there (Smith, Chouliara et al., 2016). It is useful for hospital staff to recognize the many facets of their clients' identities that exist separate from their illness and help them foster connections with people and things outside the treatment environment—this can help sustain their recovery after discharge.

Overemphasizing the physical. Closely related to the issue of dehumanization and identity loss is the narrow focus on medical and physical benchmarks to measure recovery. Given the frightening mortality statistics related to AN, it is understandable that most tertiary care programs prioritize weight gain and behavioural change (Bulik et al., 2007). However, there are downsides to an approach that emphasizes physical outcomes to the exclusion of alleviating

psychological distress, which tends to be very important to patients (Geller, Zaitsoff, & Srikameswaran., 2002). Since exclusively behavioural programs have such promising short-term results, it can be tempting for treatment providers to minimize the importance of psychological treatment; however, AN has established psychological correlates and the long-term effects of behavioural programs have not been adequately researched (Attia & Walsh, 2009). Research on the speed of weight restoration focused on the medical consequences of AN patients' rapid weight gain and concluded that there were no adverse physical outcomes (Redgrave et al., 2015; Smith, Lesser et al., 2016). However, studies also show that core problematic thought processes remained unchanged after such interventions (Fennig, Brunstein Klomek, Shahar, Sarel-Michnik, & Hadas, 2017). Since completing a behavioural intervention program is not associated with normalized views of weight and eating (Attia & Walsh, 2009; Long et al., 2012), it is probable that those whose weight increases but who have no change in psychological functioning or symptoms are more at risk for relapse (Schlegl et al., 2016).

Most researchers and experts agree there is a crucial need to incorporate psychological treatment into inpatient programs (Bezance & Holliday, 2013; Ramjan & Gill, 2012; Schlegl et al., 2016; Sheridan & McArdle, 2015; Van Ommen et al., 2009). Van Ommen et al. (2009) state, "a comprehensive treatment program for adolescents with anorexia nervosa should also give sufficient (and balanced) attention to the emotional and psychosocial functioning of patients with anorexia nervosa, as these are key long-term predictors for recovery" (p. 2806). Furthermore, patients themselves have repeatedly shared that hospital programs' overemphasis on physical recovery was distressing and increased their probability of relapse (Ross & Green, 2011; Sheridan & McArdle, 2015; Tierney, 2008). One critical component of promoting patients'

psychological wellbeing to prevent relapse is transition planning so patients do not feel abandoned once their weight falls within an acceptable range (Ross & Green, 2011).

Struggles with transition. As with any institutionalized setting, the transition from the hospital back into the community is a challenge for patients with AN (Sheridan & McArdle; Ramjan & Gill, 2012; Ross & Green, 2011). Patients are extremely vulnerable to relapse in the period following release from the hospital, especially if no plans are in place to support them through the transition phase (Ramjan & Gill, 2012; Vandereycken, 2003). Rance and colleagues (2017) warn that limits placed on the amount of outpatient follow-up are not conducive to recovery and recommend guaranteeing patients at least six months of care. Tierney (2008) found that, while social problems improved when AN patients left the hospital, food and body image concerns remained at the forefront of clients' minds.

Continuity between the care patients receive in the hospital and whatever supports are put in place to help them reintegrate into community is important. Ross and Green (2011) suggest this be achieved through communication between inpatient and outpatient programs, while other researchers emphasize the value of introducing elements of the outside world, such as normal everyday activities and visits from friends and family, into the inpatient environment (Bakker et al., 2011; Sheridan & McArdle, 2015). For example, it may be helpful to begin allowing patients to participate in some physical activity provided they are making their weight goals, so that they will be able to cope when they are no longer closely supervised (Danielsen & Rø, 2012). Vandereycken (2003) noted a 25% drop in relapse when transitions from the hospital were gradual, patients remained in group therapy, medical follow-up continued, and patients continued to attend individual psychotherapy. They also warn that limiting the length of hospitalization can lead to poorer long-term outcomes and that having patients leave before achieving full weight-

restoration is associated with a higher rate of re-hospitalization. Bakker et al. (2011) recommend gradually increasing clients' sense of responsibility leading up to release from the hospital including involving them in the design of a relapse prevention plan to increase their insight around potential triggers in the community setting.

### **Summary of Chapter 2**

This chapter introduced the study's underlying theoretical assumptions through the explication of the RCT and SC paradigms, as well as to summarize what has been found in previous studies on hospitalization for AN. I made a case for this study's relevance based on an identified gap in the extant literature. Next, I described some of the previously identified challenges to recovery young women face in the hospital, as well as some factors that support them in their healing. The next chapter will describe the methods I used in conducting this study.

### Chapter 3—Research Design and Methodology

This section describes the theoretical background informing my research methodology, then describes the procedures I followed in conducting the study. First, I illustrate the relevance of the two theories that guided my choice of methods, Social Constructionism (SC) and Relational Cultural Theory (RCT). Next, I provide a general overview of qualitative research methods and then detail the procedures I followed in this specific study, including a description of participants, how I recruited my sample, and a description of my analysis method based on Braun and Clarke's (2006) thematic analysis. I conclude the chapter by discussing issues of trustworthiness in qualitative research and locating myself as a researcher.

#### **Social Constructionism**

A SC paradigm influences how we conceptualize mental health. Rather than focusing on internal explanations for social phenomena, SC examines what occurs *between and among* individuals and *in context*, which can be depathologizing (Burr, 2003). Meanings, including those we attach to mental illness symptoms, are continually negotiated via social interaction; in AN, for example, this can refer to the way women's experiences are located within dominant social discourses about thinness and desirability (Hepworth, 1999). Gelo and colleagues (2015) argue that defining psychopathology has more to do with shifting societal values than scientific advancement.

In contrast to SC, a positivist paradigm struggles to account for the notion of personal agency, an important construct for conceptualizing recovery from mental illness (Gergen, 2011). Burr (2003) points out that the *essentialist* position, which focuses on innate traits or qualities, can be limiting and prevent hope for change. In its extreme forms, SC suggests mental illness itself is a social construct (Gelo, Vilei, Maddux, & Gennaro, 2015; Gergen, 2011; Kendall, 2013). Any attempt to explain or come up with a reason why particular people develop EDs is also a social construction (Hepworth,

1999). Gelo and colleagues (2015) distinguish between the different ways we as a society construct *psychopathology* or “the study of psychic suffering” (p. 106). A *diachronic* view, they explain, explores how society’s views of psychopathology change over time, while a *synchronic* view examines the various perspectives on psychopathology in existence at a given point in time. Both of these can be applied to AN, the conceptualization of which is far from agreed-upon in the current social climate, and which has varied over time (Gelo et al., 2015).

Several authors have used the SC paradigm to build our understanding of AN. Since societal perceptions of psychopathology shift over time, Gelo et al. (2015) take a historical look at the evolution of AN, starting with the earliest recorded cases occurring in the last half of the 19<sup>th</sup> century. Gelo et al. (2015) detail how societal views of psychopathology, in general, have evolved from magical or spiritual understandings, through deterministic biological explanations, and finally to the currently widely endorsed medical model. They describe its roots in religious fasting, based on a belief that both the body and femininity are evil and require taming through rigorous self-control. While instances of AN declined dramatically in the Renaissance era when self-starvation was equated with witchcraft, it experienced a resurgence in the Victorian era, with the emergence of the medical model of mental illness (Gelo et al., 2015). During this time, physiological explanations for AN were sought with little success, ending in the conclusion that AN’s origins are psychological and the coining of the term Anorexia Nervosa in 1873 (Gelo et al., 2015). Throughout this evolution, certain threads remained unchanged, such as the “hunger for absolute perfection” described in cases of AN throughout history (Gelo et al., 2015, p. 113).

Baerveldt and Voestermans (1996) also present a historical perspective, focusing on conceptualizations of the body in Western society, noting that the body gets only as much meaning as is attached to it by dominant discourse. They trace conceptualizations of the body

through early views that ignore both culture and the body in favour of the mind, through to the 1970s and the introduction of sociocultural explanations. This lens is a crucial one, since identity—a central concern in recovery from AN—is tied to one’s physical body (Hepworth, 1999). Hepworth (1999) goes so far as to describe AN as the inscription of sociocultural discourses onto a body; thus, the SC focus on contextual discourses and their impacts on individuals is critical in conversations about AN.

Today, various explanations for AN co-exist within the psychological literature, with most of these locating the cause within the individual (Gelo et al., 2015; Malson, Finn, Treasure, Clarke, & Anderson, 2004). Hepworth (1999) identifies that our modern world is rife with prescriptions about food, eating, and diet, but few of these recognize the social aspect of these things. Particularly for women, she explains, food is represented as tempting and sinful and eating is associated with loss of self-control. This individualization or responsibility fits neatly within the dominant discourse of Western culture, which emphasizes choice and individual actions, applauding self-mastery and control over the body (Gelo et al., 2015). Only sociocultural explanations acknowledge the influence of external structural influences on individual psychological states (Gelo et al., 2015).

### **Relational Cultural Theory**

In RCT, relational development cannot be separated from social identity (Comstock et al., 2008). Typical interpretations of AN can be criticized for reflecting dominant individualistic masculine ideas about the world in a way that oversimplifies the disorder. For example, Conti et al. (2016) describe metaphors used in treatment for AN as “adversarial, hierarchical and linear. These are characteristics of masculine metaphors, which carry undertones of competition, strife, and the binary of victory/failure” (p. 37). RCT instead emphasizes context and sociocultural factors that affect relationships, as well as the development of relational competencies (Comstock et al., 2008; Trepal et

al., 2012). RCT theorists warn that by not incorporating multicultural and social justice perspectives, we risk further marginalizing already oppressed groups (Comstock et al., 2008; Jordan, 2017; Trepal et al., 2012). Conti and colleagues (2016) state that by placing AN in a feminist context, we can “explore a greater diversity of goals and ways of living, ones that are contextually appropriate for the person and constructed in collaborative dialogue with them” (p. 38). Thus, the RCT framework acknowledges the complexity of interpersonal factors influencing AN psychopathology, shifts the emphasis from individual to collective responsibility, and opens up a greater number of options for making positive changes.

According to RCT, suffering is usually the result of isolation, while healing occurs in the context of supportive relationships (Comstock et al., 2008; Jordan, 2017). Tantillo and colleagues (2013) explain how, while many refer to AN as a disease of control (e.g., Kendall, 2013; Smith, Chouliara et al., 2016), an RCT approach views the problem as one of disconnection from others and from one’s authentic self. Trepal and colleagues (2012) explain that, although humans are motivated to connect with others, they may sacrifice connection in favour of emotional self-protection. Strategies of disconnection are a natural response to rejection or invalidation (Jordan, 2017). Trepal and colleagues (2012) conceptualize EDs as one such protective strategy that can be a defense against the pain of troubled relationships. In fact, they explain, one’s relationship with the disorder itself sometimes serves as a safer replacement for relationships with actual people.

Beyond its use as a protective disconnection strategy, AN is inherently isolating; people with AN avoid social situations for fear of being expected to eat (Granek, 2007; Trepal et al., 2012). Comstock et al. (2008) explain how avoidance of eating with others present, as in AN, leads to condemned isolation and subsequent disempowerment. These authors see condemned isolation and shame as closely associated; those experiencing condemned isolation believe there is something wrong with

them, feeling inauthentic in relationships without necessarily understanding why. Further, they explain that consistent disengagement results in self-doubt and feeling ultimately unworthy of positive relationships. While Trepal et al. (2012) acknowledge that occasional disconnection is a normal part of relationships, consistent disconnection can result in not getting one's needs met, which can lead to disguising the authentic self out of fear. Jordan (2008) notes that consistent misrepresentation of one's experience results in feeling inauthentic, helpless, alone, self-blaming, and disconnected. In AN, a series of interpersonal processes resulting in disconnection from others are commonplace; these include conflict avoidance, emotional suppression, self-isolation, and a refusal to express one's needs (Tantillo et al., 2013). Since emotional suppression is hypothesized to be at the core of AN psychopathology (Lafrance Robinson, Dolhanty, Stillar, Henderson, & Mayman, 2016; Mulkerrin, Bamford, & Serpell, 2016; Pemberton & Fox, 2011), misrepresentation or masking of one's experience is likely to leave people with AN in a constant state of chronic disconnection.

Disconnection from others is both a coping mechanism and a method of asserting control (Trepal et al., 2012). Yet it is possible to overcome the experience of chronic disconnection and this is one of the most impactful ways of deepening connection (Jordan, 2017). Experiencing a growth-fostering relationship could be profoundly healing for AN clients, since repeated experiences of mutual empathy can shift the expectation of condemned isolation (Jordan, 2017). This could be a compelling opportunity for intervention if clinicians can provide this safe growth fostering relationship. On a broader scale, marginalization is also part of the AN experience as many people with EDs report experiencing stigma from people in their lives, treatment providers, society as a whole, and even themselves (Dimitropoulos et al., 2016). A widespread shift in the way the public conceptualizes EDs may be required if we are genuinely to progress in helping people with AN.

In RCT, connection with others helps foster a sense of energy, propels us to action, develops a more accurate view of self and others, increases self-worth, and motivates us toward further connection (Comstock et al., 2008). The suggestion that developing a positive sense of oneself and one's strengths outside of the disorder is necessary for recovery (e.g., Conti, 2016; Williams et al., 2016) is consistent with Jordan's (2017) assertion that women should be allowed to embrace their abilities and strengths. Importantly for the development of successful treatment programs, "mental health professionals should include the ability to affiliate and connect with others in mutually empathic and empowering ways as an indicator of emotional maturity and psychological well-being" (Comstock et al., 2008, p. 281). Such a view is also espoused both by patients with AN and clinicians who work with them (Bakker et al., 2011; Van Ommen et al., 2009).

### **Qualitative Research**

Qualitative research aims to understand the nature and meaning of individual and group experiences (Willig, 2016). This typically occurs through the collection of stories in some form (Sanders & Wilkins, 2010). According to Willig (2016), qualitative research "seeks to capture the quality and texture of research participants' experiences and to trace the implications and consequences of those experiences in order to better understand the social and psychological processes at work" (p. 2). They note that researchers do this by examining how people interpret their own experiences, the way they describe their experiences, and how they respond to significant events. Data consist of stories or researcher observations in place of the numbers and precise measurements found in quantitative research (Willig, 2016).

Several main features distinguish qualitative research from quantitative research. Firstly, a research question guides the collection of data instead of the hypothesis in quantitative research (Willig, 2016). The research question emerges from a wish to understand some facet of others'

experience (Sanders & Wilkins, 2010). Another key characteristic of qualitative research Willig (2016) describes is the use of *inductive* methods, where themes, categories and meanings come directly from collected data. This method stands in contrast to the *deductive* approach, which slots participants' contributions into preexisting categories. Since qualitative theories and interpretations emerge from the data, their usefulness is continually tested for applicability to the context (Ponterotto, Kuriakose, & Granovskaya, 2010). Willig's final difference from quantitative research is that qualitative results are specific to the context of the study and thus cannot be widely generalized across groups or time, nor is this the goal. Instead, she explains, qualitative research collects smaller amounts of data from a specific context to examine a phenomenon in greater depth than is possible in a quantitative study.

The goal of qualitative research is not to reliably measure some variable as it is in quantitative research; that said, like all research, it requires some form of evaluation to establish its credibility (Sanders & Wilkins, 2010). Since the reliability criteria used for quantitative research are not applicable to qualitative research, it is essential for the researcher to reflect on his or her own position with respect to the research (Finefter-Rosenbluh, 2017; Sanders & Wilkins, 2010; Willig, 2016). It is necessary to make explicit the researcher's position and values in undertaking the research, as well as to acknowledge the subjective nature of reality (Sanders & Wilkins, 2010). Biases or subjectivities stem from the researcher's beliefs and life experiences and these impact their role in the co-construction of knowledge (Finefter-Rosenbluh, 2017). Furthermore, for qualitative research to be taken seriously, the researcher's position and details of the methods used must be carefully documented (Sanders & Wilkins, 2010). To adequately represent the breadth of participants' experiences, researchers should include some findings that don't match with what most participants are saying (Sanders & Wilkins, 2010).

While quantitative research has historically been dominant in psychology and related disciplines, qualitative research has increased in popularity over the past three decades (Willig, 2016). It has always been more popular in social psychology, health psychology, and counselling, compared with psychology's other sub-disciplines (Ponterotto et al., 2010; Willig, 2016). Ponterotto and colleagues (2010) follow qualitative methods' place in the counselling literature over time, noting that the origins of counselling research were in case studies conducted by pioneers in the field of therapy. Although these methods fell out of fashion with the behaviourist and cognitive therapy movements, they started to regain popularity in the 1990s (Ponterotto et al., 2010). Today, the prevalence and acceptance of qualitative research in psychology continue to grow, with new journals emerging, notable journals inviting qualitative researchers onto their editorial boards, and new interdisciplinary collaborations with qualitative researchers beginning (Willig & Stainton-Rogers, 2017).

Semi-structured face-to-face interviews are the most common type of data collection in qualitative counselling research, which is not surprising, considering similarities in the format of a research interview and a counselling session (Ponterotto et al., 2010). Ponterotto and colleagues (2010) explain, "counsellors and psychotherapists are naturally drawn to qualitative inquiry because this broad class of methods often emphasize the emotive and cognitive aspects of participants' experiences from their socially constructed worldview" (p. 8). The type of interaction typical of research interviews tends to come naturally to people who are drawn to the counselling profession (Ponterotto et al., 2010). Furthermore, participants are active in determining what is important in the study, just as in counselling. Both the researcher's and the participant's interpretation of the narrative and the research question will affect the story told in the final research product (Sanders & Wilkins, 2010). Such a collaborative approach makes

findings more applicable to counsellors and their clients outside the research setting (Ponterotto et al., 2010). Qualitative research's emphasis on subjective experience and storytelling is highly relevant to the field of counselling, and thus I deemed it the most appropriate methodological approach for conducting my study. Specifically, I chose to use a narrative approach, informed by the writings of Josselson (2011), Fraser (2004), and others, to support participants to tell their stories of AN hospitalization.

### **Narrative Research**

Josselson (2011) views narrative research as a subset of qualitative research, distinguished by its focus on narrating part or all of a person's life. Narratives are seen as a way of conveying feelings and expressing beliefs (Fraser, 2004). The fundamental idea underlying a narrative approach is that people structure their experiences into a series of stories with beginnings, middles, and ends that occur within the broader context of the institutions and systems that comprise our society (Fraser, 2004; Josselson, 2011). Fraser (2004) notes that this approach can be de-pathologizing, since it broadens the conversation about issues participants face and examines them in context. She claims the aim of this type of research is both to portray reality and to challenge the status quo and its underlying values, including social justice and self-determination. A narrative approach prioritizes participants' subjective experiences and also recognizes the subjectivity of the interviewer's perspective; through their dialogue (which includes both the interview and its subsequent interpretation by the researcher), both parties engage in the process of constructing meaning (Fraser, 2004; Josselson, 2011). This focus on constructing meaning through dialogue is consistent with the SC paradigm underlying the present research study. By valuing client stories, a narrative researcher aims to understand the meaning of their suffering (Hepworth, 1999).

Importantly, narrative research does not position the researcher as an expert; it privileges the voices of everyday people. Narrative research may use either a *holistic* approach, covering the participant's entire life story, or a *categorical* approach, comparing sections of the life narrative against similar stories (Josselson, 2011). I used a categorical approach, meaning that I asked participants to focus on their story of being hospitalized for AN, rather than their entire life story or even the full story of their ED. Some participants chose to provide context by starting at an earlier point in their illness narrative; in the interest of participant ownership in the research process, it was important to me that they were able to tell their story as they wished.

In Josselson's (2011) view of narrative research, "the self is regarded as multiple, as different voices in dialogue with one another. The narrative is conceived as a multiplicity of 'I' positions where each 'I' is an author with its own story to tell" (p. 227). This approach also examines the way a person's voice(s) interact with others in a relational context in a manner that makes space for multiple truths (Fraser, 2004). This is particularly relevant in the context of AN, where clients' voices are often silenced (e.g., O'Shaughnessy et al., 2013; Smith, Chouliara et al., 2016). The concept of interacting voices mirrors the distinction between clients' voices and the voice of the ED, which frequently appears in AN literature (e.g., Conti et al., 2016; Williams et al., 2016). O'Shaughnessy et al. (2013), Conti et al. (2016), and Papatomas et al. (2015) have all argued for the applicability of narrative research to the study of AN; this will be discussed in the following section.

Narrative research and Anorexia Nervosa. O'Shaughnessy et al. (2013) argue that a structured questionnaire format impedes progress in the field of AN research because it prioritizes the researcher's view over the participant's and leaves no space to raise other potentially important topics not in the questionnaire. Furthermore, the current predominant medical lens through which AN is

typically interpreted does not adequately account for how people make sense of their experiences or incorporate them into their overall life story (Conti et al., 2016). As Papathomas et al. (2015) point out, since the goal of narrative research is for the researcher to relinquish control to participants through unstructured interviews, it is ideally suited for overcoming these AN issues.

Chronic illnesses such as AN disrupt the life narrative and adaptation to a traumatic illness necessarily involves reconstructing life narratives (Papathomas, Smith, & Lavalley, 2015; Williams et al., 2016). Conti et al. (2016) argue that stories of AN have been oversimplified and that stories of women struggling with AN should contain paradoxical and complex metaphors that are “relational, flexible, and nonlinear” (p. 36). Typical metaphors and language in ED treatment characterize the struggle against AN as a battle or contest; the problem with this is that AN nearly always wins in this scenario (Conti et al., 2016; Williams et al., 2016). A narrative approach provides space for more nuanced stories to emerge. Conti and colleagues argue that, compared with clinical stories that focus on weight restoration, the personal stories collected in narrative research emphasize health, hope, and facing adversity.

Research overwhelmingly shows the voices of women with AN are discounted because of the disorder (Kendall, 2013; Malson et al., 2004; O’Shaughnessy et al., 2013; Smith et al., 2016). Furthermore, Malson et al. (2004) found that, when this occurs, there is a tendency for these women to shut down and disengage from treatment. They require a platform for their voices to be heard if understanding of AN is to progress. Narrative analysis is a rigorous way of prioritizing these women’s previously marginalized voices (Conti et al., 2016).

### **The Present Study**

Given the relatively scant literature on best practices in inpatient care for AN, more research in this area is needed to guide service planning for hospital programs. Since motivation is predictive of

recovery (Hillen, Dempfle, Seitz, Herpertz-Dahlmann, Bühren, 2015), the views of AN participants in these programs is a critical missing perspective. Sheridan and McArdle (2015) assert that qualitative research on participant experiences of services could address this gap. Olmsted et al. (2010) highlight the lack of existing research on the efficacy of current residential treatment practices for adolescents with AN. Attia and Walsh (2009) observe that there is little research on non-medical interventions such as “the resolution of underlying psychological difficulties” (p. 501). While considerable quantitative research in this area exists (e.g. Berkman, Lohr, & Bulik, 2007; Bulik et al., 2007) no factors have consistently been associated with positive or negative outcomes. Thus, qualitative investigation of factors related to AN recovery is needed. In the present research, I examined what factors in inpatient care participants associated with achieving desired outcomes. While a few studies have investigated participants’ experiences in specialized inpatient programs for EDs (e.g., Van Ommen et al., 2009; Ramjan & Gill, 2012), many AN patients are treated on general medical wards and this experience can be entirely different. The purpose of the present investigation was to explore factors that young women with AN perceive as helpful or not helpful in non-specialized hospital settings, using qualitative interviews. The research question was *What are AN participants’ experiences of helpful and not helpful factors in hospitalized care that affect recovery, motivation, and subjective well-being?* A primary objective of this research was to add the conspicuously absent voices of young women who have been hospitalized for AN to the existing literature on hospital care provision. I chose a narrative approach to prioritize the views of eight young women struggling with AN in order to add their perspectives to the existing body of literature regarding AN treatment, with particular emphasis on factors that helped or hindered their recovery. Additionally, this research contributes to knowledge of effective treatment practices in inpatient care, as well as how relational and SC lenses can illuminate ED recovery processes.

## Participants.

*Recruitment.* After obtaining approval from the University of Victoria Human Research Ethics Board, participants were recruited from across Canada using a recruitment poster (Appendix A), which I posted in local businesses and community centres, as well as online via the BC Centres for Excellence in Eating Disorders Web Portal, the Centre for Youth & Society web page, and on Facebook. Additionally, counsellors in private practice specializing in EDs gave my contact information to their clients. I also used snowball sampling, inviting practitioners and participants to share the poster or my contact information with others who may have been eligible to participate or may have known someone else who was eligible to participate.

The research poster specified that I was interested in collecting stories from young women aged 17–25 who had experienced hospitalization for AN and had been out of the hospital at least six months in order to have had time to reflect on their experiences. I selected this age range because I was interested in the developmental concerns and perspectives specific to adolescence and young adulthood, especially that of identity formation, and how this would impact participants' experiences. Since AN's typical onset is during adolescence (Salzmann-Erikson & Dahlén, 2017), identity concerns are a salient concern for many AN clients. Additionally, the focus on identity construction is relevant to the underlying SC and RCT theories. While AN affects both men and women, I chose to focus on young women, since AN occurs more frequently in women and I was interested in the gendered nature of participants' experiences, as outlined in the RCT framework (Trepal et al., 2012).

Young women interested in participating in the study contacted me directly via email or telephone. When potential participants made this initial contact, I emailed them a copy of the recruitment letter (Appendix B). I reviewed the eligibility criteria, explained the interview

process, and invited them to ask any questions or voice any concerns. Two volunteers were not eligible, because they had only attended specialized inpatient programs for EDs. I scheduled interviews with eight volunteers who met the criteria and wanted to participate. I then e-mailed them the consent letter (Appendix C) and the interview question (Appendix D).

*Final participant group.* Participants were eight adolescents or young women aged 18–24. Participants' time in the hospital ranged from two weeks to seven months. Two participants reported single instances of hospitalization, while the remaining six reported at least two, but sometimes multiple, different admissions (the range was 1–4). Participants came from three Canadian provinces.

*Interviews.* Data collection consisted of one research interview with each of the participants. Interviews took between 45 minutes and 100 minutes and were conducted via Skype teleconferencing technology. The length of the interview depended primarily on the amount of time the participant found necessary to tell her story in a way that felt complete. In some cases where I felt the level of detail was insufficient to fully understand the participant's experience, I used clarifying questions, such as "can you tell me more about that?", to expand on or deepen their stories.

Prior to the interview session, I asked each participant to read the informed consent letter (Appendix C). I again invited participants to ask me any questions about the research process, the project's ethical approval, or any other concerns they might have via email. At the start of the interview, I reviewed the consent form, verbally informing participants of the limits to confidentiality, as well as their right to withdraw or refuse to answer any questions without explanation or consequences. I encouraged participants to pause the interview if they thought of further questions they wished to have answered. Once participants confirmed that they had read and understood the informed consent document and that they had no further questions about their

involvement in the research, I asked them to sign the consent form, take a photo or scan the document, and e-mail it back to me. Throughout the interview, I used the attending and active listening skills I learned throughout my two years of counselling training to monitor participants for signs of distress. When one participant showed signs of distress, I paused the interview and offered to provide a referral to appropriate supports—however, she declined the referral, said she wanted to continue, and was able to complete the interview.

The interview guide consisted of one open-ended item, asking participants to share their story of being hospitalized for AN: “I’d like to hear your story of being hospitalized. I’m particularly interested in the things that you thought either helped or got in the way of your recovery, some of the things that hospital staff specifically did to help or hinder your recovery? What practices would you like to see changed in hospital programs for youth with Anorexia Nervosa? What would you like to share with the people that design hospital programs for Anorexia Nervosa?” (see Appendix D). Follow-up questions and prompts (e.g., Can you tell me more about that?) were used to gain a clearer and more detailed understanding of participants’ experiences. Importantly, the use of a single research question and minimal direction from me encouraged participants to take ownership of the interview process and focus the interview on the parts of the story they deemed significant. This is of particular importance in AN; research shows that choice and control are important aspects of EDs (e.g. Kendall, 2013; Smith, Chouliara et al., 2016) and patients with AN have indicated in previous research that their voices were discounted in the diagnosis and treatment of their ED (Kendall, 2013; Malson et al., 2004; O’Shaughnessy et al., 2013; Smith, Chouliara et al., 2016). Accordingly, I specifically wanted to direct the narratives as little as possible; the participants all had the question in front of them as they spoke and could refer to it if needed.

At the conclusion of the interview session, all participants agreed to be contacted regarding any follow-up clarification questions that arose as I transcribed and analyzed the interviews. I also encouraged participants to contact me if they remembered additional details they wished to include. Once transcripts were complete, I summarized each interview into a brief “ghost story” (process described below), which I then emailed to participants to give them an opportunity to provide feedback. Two participants responded with amendments to their ghost stories, which I incorporated in the final versions. Two participants could not be contacted following the interview, and one declined to have a ghostwritten account of her narrative included in the study (but agreed to have her interview data included); these three participant ghost stories were omitted. The remaining five ghost stories appear in Chapter 4.

Analysis. The data analysis procedures in this study involved first reviewing interview tapes for holistic impressions (e.g., “identity is central in this narrative”, “participant makes frequent reference to relationships with particular staff members”), then transcribing the interviews, coding the data line-by-line, and grouping similar data codes into themes (described in more detail below). My process was guided by Braun and Clarke’s (2006) thematic analysis procedure, which is designed to be applicable across a wide range of qualitative methods. Other AN researchers have deemed thematic analysis an effective way to explore how metaphors, feelings, and experiences interplay in young women’s attempts to make meaning of their illness (Conti et al., 2016). Conti et al. (2016) state that, “Thematic analysis is a particularly useful method for understanding organizing principles, patterns and interaction both within and across participant interviews” (p. 39). The purpose of thematic analysis is the identification of interview content patterns to structure data into a framework that describes the entire data set (Braun & Clarke, 2006). This process takes into account individual participant meaning-making,

similarities among participants, and the influence of society on those meanings. The emphasis on societal impacts on knowledge construction makes this method a good fit with the SC lens of the study. Braun and Clarke's (2006) process involves identifying data codes, grouping them into themes, and reviewing and naming the themes.

Braun and Clarke (2006) suggest transcribing interviews as close to word for word as possible. Qualitative researchers acknowledge transcription as part of the analysis (Davidson, 2009; Skukauskaite, 2012); the act of transcribing necessitates choices about how to represent the myriad features of spoken communication that are typically absent in written text, including which to omit (Davidson, 2009). Because it is a critical step in analysis, a substantial number of researchers advocate for the researcher to do his or her own transcribing (Davidson, 2009; Fraser, 2004; Skukauskaite, 2012). Furthermore, even once representational decisions are made, no two transcriptionists will hear and then portray an interview in precisely the same way (Davidson, 2009). For these reasons, I chose to transcribe my own interviews.

Davidson (2009) warns that failure to make transcription procedures explicit detracts from the research credibility. My process began with listening to all the interviews twice to familiarize myself with the data set as a whole, paying particular attention to meaning and commonalities and making notes (Braun & Clarke, 2006). Next, I used VLC software to slow the interviews to a speed at which I could type. I made note of any part of the recording that I could not understand. Once I typed the entire interview, I started at the beginning and corrected any spelling mistakes without listening to the tape. Finally, I replayed the tape once more, filling in any words I missed during the initial transcription. Once each transcript was complete, I read it from start to finish to gain an overall sense of the narrative. Depending on the length of the interview, this complete transcription process took from 5–10 hours per participant.

Davidson (2009) also speaks to the necessity of connecting transcribing decisions to the theoretical background of a study. She distinguishes between naturalized transcription, which is made to resemble written speech through the use of correct grammar and punctuation, and denaturalized transcription, which remains more faithful to the spoken word upon which the transcript is based (e.g., retaining verbalizations such as “um”). Denaturalized transcription is more consistent with the SC framework, in that it is utilized by researchers who subscribe to the view that verbal interactions are a means of constructing reality (Davidson, 2009). Davidson acknowledges that naturalized and denaturalized transcription are two ends of a continuum, and most transcripts fall somewhere in the middle. For the sake of readability, I did use certain conventions of written text in my transcripts, such as separating participants’ longer comments into sentences. However, I tried to remain true to the recordings in my inclusion of word repetitions, stutters, “ums,” and selected inflections I believed would impact the understanding of participants’ comments (i.e., [SARCASTICALLY]), in accordance with the denaturalized transcription tradition. Another significant step was removing the names of people, places, or organizations mentioned by participants for the sake of confidentiality. In accordance with both the SC and the RCT frameworks, it is important that I acknowledge my own and my participants’ roles in the construction of the interview stories represented in the final transcripts. While the stories belong to the participants, I recognize that having me as an audience will have impacted the way in which participants chose to tell their stories. Also, my own interpretations, experiences, assumptions, and subjectivities will have affected the way I understood what participants shared; all this had an impact on how I represented stories in the transcripts (Skukauskaite, 2012).

The next stage of my analysis was using a *ghostwriting* process to create a summary of each interview (Rhodes, 2000). Ghostwriting is intended as a way of managing the subjectivity inherent in qualitative research. In ghostwriting, rather than using direct verbatim quotes from the participant transcript inserted into descriptive text, the researcher, using paraphrases and participant words, constructs a narrative that is something co-authored by researcher and the participant. Rhodes (2000) developed this process to deal with problematic aspects of transcription and quoting participants. He explains, “The danger of using...transcripts is they obscure the constructions of the researcher by (re)presenting the interview in a way that appears to show a reflection of actual events” (p. 519). Transcription can remove the context from an interview and thereby strip it of important meanings; in contrast, ghostwritten stories recognize research interviews as performances embedded in the contexts within which they are shared (Rhodes, 2000). I chose to include both short ghostwritten stories and a thematic discussion with embedded quotations from the transcripts in presenting my findings, to capitalize on the strengths of both. I invited each participant to select a pseudonym to be used to identify them both in the ghostwritten narratives in Chapter 4 and the illustrative quotes in Chapter 5. Three participants chose their own pseudonyms, two could not think of pseudonyms and asked me to choose for them, and three did not respond and therefore I chose for them. Part of the ghostwriting process is to present the story to the interviewee to evaluate and give their feedback, then incorporate any suggestions back into the narrative (Rhodes, 2000). After each ghostwritten narrative was complete, I emailed it to the participant for review. Two participants made minor revisions to the ghostwritten stories; three left them as they were. Two participants could not be contacted, and one chose not to have her ghost story included in the research. Thus, I excluded three ghost stories from the study; the remaining five appear in Chapter 4.

My next step was to review the interview transcripts to identify codes and then themes. A code is the smallest unit of information that contains meaning, while a theme is a grouping of related codes, defined as a characteristic response pattern across participants (Braun & Clarke, 2006). The relationship of each theme to the larger research question determined its importance, rather than strictly prevalence in the data. I identified themes in the data by way of what Braun and Clarke (2006) term an *inductive* or bottom-up process. This means participants' responses to the research question determined what themes were present in the final analysis (rather than looking for pre-determined themes—a deductive process). It is important to note that, while the inductive approach aims to avoid steering the analysis in a particular direction, the researcher is always influenced by her theoretical background and guides the interview and choice of themes to some extent (Braun & Clarke, 2006; Sanders & Wilkins, 2010). Constructionist thematic analysis uses a latent approach, meaning that the aim is to look at meanings, ideas, and concepts underlying what the participants are saying rather than simply describing the surface level meaning of participants' contributions (Braun & Clarke, 2008). Furthermore, there is an emphasis on putting individual narratives into context, taking into account sociocultural factors and structural conditions. After identifying preliminary themes, I used an iterative or “back-and-forth” process, retaining only themes supported by the data and checking that each theme was, in fact, distinct from others. I compared descriptions of each theme against excerpts from transcripts that pertained to these themes to determine whether the theme captured what participants were saying. Where this was not the case, theme descriptions were adjusted and renamed accordingly. Remaining themes after this process were those that coherently described a significant facet of participants' experiences (internally homogeneous) and were clearly distinguishable from one another (externally homogeneous; Braun & Clarke, 2006).

## **Establishing Trustworthiness**

Although qualitative research has gained greater acceptance in recent decades, Nutt Williams and Morrow (2009) warn that concerns remain regarding its credibility. They caution that only scientific rigour separates qualitative research from anecdotal evidence and thus instruct qualitative researchers to demonstrate they have followed the appropriate procedures in selecting their rationale, describing their methods of recruiting participants and interpreting data. In quantitative research, there exists a well-established language for communicating about the trustworthiness of the study (e.g. validity, reliability); in contrast, qualitative researchers do not have a common language for this purpose (Nutt Williams & Morrow, 2009). Theorists have struggled to establish a vocabulary for evaluating trustworthiness in qualitative research because of the diversity of methods that fall under its heading (Nutt Williams & Morrow, 2009).

Nutt Williams and Morrow (2009) break qualitative research trustworthiness into three categories: data integrity, reflexivity versus subjectivity, and communicating findings. *Data integrity* refers to the dependability or adequacy of the data. The first step of ensuring integrity these authors identify is to clearly explain one's methods so others may replicate. For this reason, I outlined my method in the previous sections of this chapter. Another aspect of ensuring integrity is adequate data collection, which can be determined by soliciting feedback from a more experienced researcher (Nutt Williams & Morrow, 2009). I chose my sample size in consultation with my thesis supervisor, who has several decades of experience conducting and supervising qualitative research. To further demonstrate the integrity of the data, Nutt Williams and Morrow argue, researchers must prove their interpretations are supported by the original data; one method of doing this is by illustrating with quotes. In Chapter 5, I present my analysis of the interview data, accompanied by participant quotes that support my interpretations.

The second principle Nutt Williams and Morrow (2009) emphasize is that of researcher reflexivity. While all research is inherently subjective, an attempt must be made to address researcher bias through reflexive practices, aiming to foster self-awareness. Finefter-Rosenbluh (2017) defines reflexivity as an ongoing dialogue with oneself and a commitment to self-monitoring regarding one's position in relation to the research. The goal of reflexivity, according to Nutt Williams and Morrow, is to determine what comes from the participant as opposed to from the researcher. Reflexive practices they identify include journaling and bracketing biases in advance of doing the research. I kept a journal throughout the research process where I reflected on my experiences. Another essential practice for a qualitative researcher is *self-location* or outlining one's own position in relation to the research to make explicit potential sources of bias (Nutt-Williams & Morrow, 2009; Willig, 2016). The next section is my self-location, where I acknowledge the background experiences I bring to the project. Another method of minimizing subjectivity in the research is through *member-checking* or asking participants for feedback throughout the research process (Nutt Williams & Morrow, 2009). While I chose not to have participants review transcripts as this would be too onerous, I gave participants an opportunity to read and provide feedback on the ghost stories presented in Chapter 4. Furthermore, according to the SC and narrative research paradigms, the construction of meaning is considered a fluid and dynamic process. The idea of member checking for factual accuracy, as in the reading of transcripts, implies that the research aims to represent the one true version of the participant's narrative, while both SC and narrative research would argue there are multiple truths (Gergen, 2011; Josselson, 2011). While none of the participants chose to remove any information from their ghostwritten stories, two of them sent additional information they wished to include.

Finally, to be trustworthy, qualitative research should be communicated to the appropriate audience(s) in accessible language and applied in a useful manner. Nutt Williams and Morrow

(2009) argue that qualitative research should be judged on whether it has *social validity* or contributes something of value; ways of achieving this include improving outcomes, identifying limitations in existing approaches, promoting dialogue, revealing new courses of action, or advancing social change. My hope in conducting this research is that it will do all five of these things. The dialogue with the eight young women who participated illuminated problems with the treatment they received and yielded suggestions for new ways of supporting young women with AN. Ideally, this will spark a broader conversation contributing to improvements in the way programs are designed. My attempt to privilege the voices of these young women is part of a widespread movement within social science research, and particularly within the qualitative tradition, to bring previously marginalized people's perspectives into the literature (Manning & Kunkel, 2014).

Regardless of a research project's social validity, it is of little use unless it is well communicated. Interpretations of the research should be understandable to readers and backed up with quotations from the participants (Nutt Williams & Morrow, 2009). Quotations from this study's participants appear throughout the discussion of the research results in Chapter 5. Nutt Williams and Morrow (2009) add that researchers should explain the relevance of their findings to contemporary theories and practice by citing other research. I provide such explanations throughout Chapter 5. After completion of my thesis, I plan to write an accessible summary of the main findings that will be shared with counselling practitioners and write a paper for publication; these actions will facilitate reaching wider research, training, and practice audiences.

### **Researcher Location**

Multiple parts of my history impact how I approached this research project and I will now discuss how I believe each one impacts my perspective. Firstly, I come to this project with four

years of experience as a research assistant on qualitative studies and two years of graduate school, including formal classroom instruction in qualitative research methods. My work on previous qualitative projects and the knowledge I gained from my academic program were valuable experiences for understanding theoretical frameworks, appreciating mental health issues, conducting research interviews, and participating in qualitative analysis.

Secondly, my clinical work experiences impact my perspective on this research project's population. As part of my Master's in Counselling Psychology program at the University of Victoria, I completed a nine-month internship at the Fraser South Eating Disorder Program. In this role, I counselled several young women with AN, some of whom were hospitalized as part of their treatment, either before or during the time I worked with them. Conversations with my supervisor at this internship influenced my decision to focus my thesis on this topic. Further, my work with clients at that site enhanced my understanding and broadened my vocabulary related to the topic of EDs and may have influenced the types of clarifying questions I asked during interviews and interpretations I made during the analysis.

The third and final lens I bring to this project is my own experience as a young woman hospitalized for AN. During my adolescence, I was diagnosed with AN and spent two weeks in a pediatric ward at my local hospital. In this sense, I came to this project as what is known in the field as an *insider researcher*, or a member of the population under study (Finefter-Rosenbluh, 2017). There are advantages and disadvantages to this position. I believe my personal experience enhanced my capacity to empathize with participants and helped me build trust and safety, making them more comfortable disclosing their experiences. I briefly disclosed my personal history of having an ED and being in the hospital at the start of each interview as part of my explanation of my rationale for conducting the study. None of the participants commented

directly on my disclosure nor asked any questions about my experience. Research suggests trust is more easily built by insider researchers and participants are often more willing to share with others who have had similar experiences (Corbin Dwyer & Buckle, 2009; Finefter-Rosenbluh, 2017). Corbin Dwyer and Buckle (2009) note that participants and insider researchers share a common language that can expedite the research process. Further, Finefter-Rosenbluh (2017) suggests insider researchers may be more aware of what is relevant to participants.

My proximity to the topic also had its disadvantages. For example, it was imperative to me to incorporate reflexivity to a greater degree than would be necessary for an outsider researcher. Corbin Dwyer and Buckle (2009) warn that failure to separate one's personal experience from participants' can be a problem for insider researchers and lead to making unwarranted assumptions. These assumptions can impact the direction of the interview or its analysis. While I had some degree of control over my own perspective on the research, a factor I could not control was my participants' perspective. Corbin Dwyer and Buckle also caution that participants may make assumptions about the researcher's understanding based on their insider status and therefore not explain their experience in as much depth. I attempted to gain a robust explanation of participants' experiences by asking clarifying questions but it is possible that some participants might have explained aspects of their experience more fully to an outsider researcher.

It is important to acknowledge that insider and outsider researcher are terms meant to illustrate a point but that, in reality, no researcher's experience will ever be exactly the same as nor perfectly distinct from that of his or her participants. Corbin Dwyer and Buckle (2009) comment, "we may be closer to the insider position or closer to the outsider position, but because our perspective is shaped by our position as a researcher...we cannot fully occupy one or the

other of those positions” (p. 61). For example, while my experience may have been very similar to that of some participants in my study, my hospitalization was several years further in the past than any of theirs and, thus, I am further removed from the experience than them.

Insider researchers frequently face stigma in that outsiders can assume their subjectivity is a negative bias that makes the research findings less valuable (Corbin Dwyer & Buckle, 2009). Some express concern that a researcher’s personal experience with a topic will compromise their objectivity; however, as noted above, an objective, unbiased account of participants’ experiences is not possible in qualitative research, nor is this its goal (Sanders & Wilkins, 2010). In fact, my position as an insider researcher led me to contemplate my assumptions and biases on a deeper level than I might have if I were approaching this project as an outsider. Therefore, I believe that, with this high degree of self-awareness and reflexivity, it was appropriate for me to conduct this research and could, in fact, be advantageous given the aforementioned benefits of insider research.

### **Summary of Chapter 3**

In Chapter 3, I outlined the relevance of SC and RCT to the current research project. Next, I provided an overview of qualitative research and then turned to a more specific description of narrative research. I discussed the relevance of this approach for AN, referencing previous narrative research with this population. After that, I described the methods I used in the present study. I described my recruitment procedures and final participant sample, then explained my data collection, which involved qualitative interviews with each participant. I explained my use of Braun and Clarke’s (2006) thematic analysis procedure and the inclusion of Rhodes’ (2000) ghostwritten narratives as a means of representing a version of each participant’s story. Finally, I

discussed issues of credibility and concluded the chapter by locating myself as a researcher. The following chapter will present five ghostwritten narratives based on the research interviews.

## Chapter 4—Participants' Stories

This chapter contains summarized versions of participants' narratives. These stories were constructed based on Rhodes' (2000) ghostwriting method, which serves the dual aims of capturing the participant's voice to the extent possible, while also acknowledging the inherent influence of the researcher on the constructed narrative. Rhodes recognizes that these summarized versions of participants' narratives cannot portray the level of detail of the full research interview, nor the individual voice of the participant; however, every effort was made to preserve the participant's own words and unique phrasing. Each ghostwritten narrative contains a linear recounting of the participant's hospitalization journey from wherever they chose to begin sharing and proceeding in chronological order. In reality, the research interviews did not always progress in this linear fashion; however, I chose to present them in this way to aid readers' understanding. I invited participants to review the ghostwritten narratives once complete, to confirm they were satisfied with the representation of their narrative. Since I was unable to contact two participants (Brittney and Jordana) to review their summarized stories and one participant chose not to have her story included (Amelia), these three participants' narratives are excluded from this chapter. The remaining five ghostwritten stories (Kate, Eleni, Nicole, Astra, and Mira) are presented below.

### **Kate**

I was first hospitalized when I was 13 or 14 in a pediatric ward at my local hospital and that was traumatic. My parents saw me getting dangerously underweight, so they took me to an outpatient program and they sent me straight to the hospital. I was on bedrest and my family had to pay extra for a private room across from the nurse's station so they could provide one-on-one supervision. The bathroom was locked, even though purging wasn't an issue for me at that point.

I wasn't allowed to have a cellphone and only my family could visit. I wasn't eating anything—just supplements—even though I begged them to let me eat real food. Eventually, I shut down and stopped talking because I didn't trust the staff. My parents signed me out after a month because we had all had it. We did a version of family-based therapy for the next seven years. I wasn't recovered but I could function.

Three years ago, at age 20, I relapsed badly and went back to the outpatient program. I was on a waiting list for an inpatient program but got sent to the ER three times before they finally decided to admit me. The doctor was nice but made me feel like a burden to the system. That was hard, to feel like my illness was invalidated. I was on an overflow unit, in a room with a window to the nurse's station and brought to the hallway to eat, which was helpful, because if they left me, I would throw it away. Some nurses coached me through it but mostly they just didn't know what to do with me. I'd be doing laps around the floor and they would just watch me go by. When that kind of care wasn't seen as important, the eating disorder would come in, saying, "If you were really sick, they would care." Finally, this one social worker came in who had experience with eating disorders and had had an eating disorder herself, so she was really in tune with everything. She educated the staff and told them what I needed. After that, I had to ask to go to the washroom and keep showers to 10 minutes long because, by then, I was purging. If I was pacing, I was told to sit down. Things like that.

My next hospitalization was traumatic to the nth degree. I would get into fights with the doctor and eventually he just stopped showing up. They put in an NG feeding tube and I was screaming and crying to get it out because I was in so much pain, but of course they wouldn't listen to me because they thought it was my eating disorder that wanted it out. I was there for

three weeks and eventually just decided to gain the weight so I could go home. Once I did, I relapsed really badly and was admitted to a specialized program for three months.

After I left the specialized program I started relapsing pretty much right away. I was sent back to the hospital another three months later. That time was better, because this doctor knew he didn't have experience with eating disorders, so he let the social worker come up with a plan. They set the ward up in a way that would keep me from slipping back into old behaviours. It worked but it was very inconsistent, depending on whether the nurses applied what was prescribed. I had a lot of family friends come and eat meals with me. I don't think I would have made it without all that support. The social worker was just amazing.

I was there for a month, relapsed, and ended up back for a week. Thankfully, it was the same doctor and social worker so I didn't have to worry about what they were going to say or re-explain my whole story. They put me straight on the NG tube because I'd relapsed too fast. Afterwards, I got transferred there to another specialized program, which I ended up leaving and getting really sick again. I was thankful that the doctor and social worker had done what they did, even though I fought against it the whole time, because otherwise I don't know if I would have made it to where I ended up. I recognize that hospitals saved my life and, when the eating disorder takes over, it is sometimes necessary but I wish my experiences in hospital could have been less traumatic, tumultuous, and dehumanizing. Rather, I think I would have responded quicker to the compassionate and supportive care that any ill person deserves.

### **Eleni**

All my life I was insecure, but Anorexia was sparked at the age of 13, in the midst of my parents' divorce. I grew up being told I was a spitting image of my father with similar talents. During the divorce, he became mentally and verbally abusive, causing me to want to become

everything he and I held in common. I tried to restrict my calories, trying to eat more healthy, and eventually was put into a day hospital, where I was seen by an art therapist, a family therapist and a doctor. I didn't want to share what I was going through because they would ask me ridiculous questions. They were all saying that the eating disorder was because of the divorce but I knew it had been lingering way before.

I got diagnosed with depression and Anorexia Nervosa and, at age 15, I was hospitalized for a couple of months. I was confined to a bed for a couple of weeks and I think I almost went ballistic. I wasn't allowed to use Facebook or anything like that, so I had no association to any friends. I could only see immediate family for one hour a day and only up until a certain hour. It was difficult, because I was alone most of the time. The ward had just one other eating disorder patient. I didn't want to share with her or hear her story, because I saw that she was young and easily influenced. In the back of my mind, I was thinking she was much thinner than I was and I wanted to be that. The nurses weren't mean, but they weren't nice. The ones who did not know me would call me, "the anorexic one." It was frustrating to be called what I was suffering and not by my name. I did have the teachers at the hospital visiting me and then I would have therapy. It was like prison. I could not understand how they could not let somebody walk around or get a breath of fresh air, even call my mother when I needed her. If you did what they said and were a good patient, you'd get out. I learned that I had to keep my mouth shut and just get out, which is what I did.

After I gained back my weight, I went back to the day hospital, teeter-tottered from there for a couple of years, and then I was sent back to the hospital a second time when I was 17. It was the same process again with the same staff; we did the whole 360. That was just going through the motions every day. I had no concept of whether I wanted to get better, whether I

wanted to get worse. I was just trying to find a middle ground between everything and then I got out a second time. I was in my second to last year of high school and, finally, I got to a point where they said they couldn't deal with me anymore, so they sent me to a day program at a mental health institution. I lost more weight and then was put into the inpatient program at the mental hospital.

Even today, I still struggle with it. I'm in a much better place, all thanks to myself. I haven't had any help since the age of 17. I'm 24 now, still struggling with it. My father and I have a better relationship, exemplifying how this wasn't the cause. However, everybody in my life is kind of done with me. I am currently trying to manage myself and not be in "the danger zone," because I see my issue like a regular one. Everybody has problems. I work. I'm doing my bachelor's degree online. I am leading a life. I'm just, unfortunately, still struggling with my weight and to try to find social connectivity again but I'm trying to reach a better life.

### **Nicole**

I got really pretty sick when I was 17 and I fainted multiple times and I would go to the hospital in an ambulance. It was probably the sixth time that they finally admitted me but it was obviously against my will. I was *formed*, which meant I was there on an involuntary basis, so even if my mom wanted to take me home she couldn't. I spent three or four days in the emergency area because they were waiting for a bed. On the fifth day, when I wouldn't eat, they put a feeding tube in me and, again, that wasn't my choice. Every hour, a new person would come in and try to talk to me and they weren't really consistent. For snacks you could only have 15 minutes to eat, and meals you could only have 30 minutes and if you weren't done in 30 minutes, they would just take your food from you. Because it was like jail for me, I was trying to get off my form so I could go home, so I was actually trying, but they were taking my food away

and it was dumb. It was just all about weight, I realized, if I wanted to go home on a weekend pass. The longest pass that I got was four hours and that was on Christmas Day. I felt that I didn't belong in the hospital because the other girls on the ward were all younger and it really wasn't comfortable because we weren't allowed to talk to each other. Nothing about the setting was normal.

In the end, they kicked me out for being noncompliant because I wouldn't eat something that they asked me to. I didn't mind because I wanted to leave but my mom was yelling at all the nurses that she wanted me to stay. I was discharged right before my 18<sup>th</sup> birthday and I wasn't even allowed to go back in when I got sick again, because it was too close to my 18<sup>th</sup> birthday. They sent me to an adult hospital but that orientation was the scariest thing of my life, so I never actually went there. At the same time, they made me go to the outpatient program once I was kicked out. I just realized that in Canada, we really need a whole different system for people with eating disorders. There needs to be a transition stage for when you turn 18. You're basically dropped off the face of the earth and you have to start over.

### **Astra**

My eating disorder started around 16/17 but, as we all know, it goes back a number of years. I was in high school and it was pretty easy to hide because it never got super severe and I was an athlete. It wasn't until I went away to university that it really got bad, because that's when I was on my own. First year university was kind of, like, a bit of up and down and I was all over the place, followed by doctors who had no clue about eating disorders. In second year, I just went downhill very quickly and when my parents saw me they freaked out and took me to my family doctor who sent me home without even doing a full assessment. I went back to school until my parents threatened to bring me home if I didn't go to the hospital to get checked out. My

heart wasn't okay, so I got admitted to a general ward and that was an awful experience, because I didn't even get the option to eat. They put me straight on an NG feeding tube. Eventually, a bed opened up on the pediatric ward, which was somewhat better. Still, the minute I was not certified, I discharged myself, but on the condition that I had to go to a residential treatment program if I wanted to go back to university.

In that program, I was exposed to other girls, so I learned a lot of tricks and it felt like this competition. I stayed there for four months and got weight-restored. I got a lot out of it but I also was just not ready to get better and, the day I left, I was on relapse mode so within three weeks, I was back in the hospital. At this point I was 19, so I should not have been on the pediatric ward but I was. I had an awful experience, because I was certified and the staff weren't happy to have me there because of my age. I was able to get away with a lot, because they weren't checking up on me as much. They let me join some groups with the other girls but, through that, the bulimic girls showed me bingeing and purging, which I had never really heard of before. I was too scared to do it in the hospital but, again, the minute I was uncertified, I discharged myself and got into bingeing and purging. I was very quiet about it, so my parents didn't know. They just saw me eating and thought I was better. Then my weight started dropping again and I liked that but that's when I started feeling the sickest.

The next couple months were me going downhill, going to an outpatient program until I could get into the adult specialized inpatient program, which takes forever. When I got in there, that actually opened my eyes to a lot, because I saw women in their 60s struggling with this illness and I knew I didn't want that to be me. I stayed there for a month and a half and when I got out, I asked to try going back to school. Everyone told me I wasn't ready and I found that hard because I did feel ready. People were so on-edge about me coming back and it felt like

everybody was walking on eggshells. I just didn't feel as comfortable as I thought I would feel and so I started to slip very quickly. I was seeing a psychiatrist at the university and he recommended I go into the hospital there but at this point it was my choice. I knew I couldn't focus on school anymore and to be honest I just wanted out of the house, so I said yes. It wasn't bad there but, over time, I started gaining weight and had this massive meal plan, so I started throwing up again. I got to my healthiest weight since the residential treatment program, then I left and made the decision not to go back to school, that I was going to go home and work.

The next year and a half, I was keeping myself afloat. I still found it challenging with my family and there was a lot of fighting, so over time, I started to struggle a little bit more and slowly started going downhill again when I was 22. Eventually, I decided I was tired and needed more help. I went back to the outpatient program and asked them if I could go back to the adult inpatient program and they said no. They looked at everything I'd already done that hadn't worked and told me I had to get to a healthy weight on my own before they'd let me back in. I begged them because I knew I actually couldn't gain the weight on my own; anytime I tried, I got back into the bingeing and purging but they wouldn't change their minds.

That's when my therapist introduced the idea of family-based therapy and I felt forced into that, because otherwise I would wind up back on the medical ward eventually. It didn't go well because I knew all the tricks of the trade. I was just so resentful and the only thing it helped me do was put on the weight. I did start to feel better and, when I cut ties with family-based therapy I started looking at what other options might be out there but I still never fully wanted recovery until very recently. I finally feel like I'm really ready to do all this stuff and I want to have a life. I understand after all these years of therapy why I do what I do and I almost feel like no one else can believe that. I'm in this place of trying to figure out what to do next. I just basically need a

boost to at least get my brain to a better place because I know that, in three years, I do want to be someone who's happy and healthy. It was not until I realized my losses...school, friends, family, my hair, bone density, period...there was nothing really left that made me, me. Only when I saw the damage, I was able to begin taking the steps towards recovery.

### **Mira**

I was admitted when I was 15 and had my 16<sup>th</sup> birthday there. The biggest thing for me was that I hated being around other girls. They would just say things that were so negative and it wouldn't be necessarily towards me but I felt like should be thinking in the same way. At the start, I just had the eating issues but when I got in there I started developing other things like depression and anxiety. It's that group mentality. I feel like that's just, like, the disorder, though. You're not supposed to be even living at that weight and at the end of the day, we were a bunch of teenage girls being confined, basically, to this prison cell. There was so much I learned there about maintaining that unhealthy mindset and not even from the other patients—from the doctors. They would restrict me from doing things and then tell me why. I was very lucky in that I never developed the bulimic tendencies and that meant I had less restrictions than some people but it still was like this prison.

The nurses weren't very compassionate towards us. They were so quick to take away privileges, using that as leverage to make us eat. My counsellors and psychologists would try to tell me things about how I should identify myself. I feel like people feeling entitled to tell shit about me in that sense took away my power to identify how I pleased. Overall, improvements needed to be made and, given that we were in there as psych patients, the kind of changes we wanted to see were just taken as skewed reality. Some of the other staff were nicer. They were very good about talking with us rather than about us. They would sit us down and ask us how we

were doing and call us on things in a compassionate way, like a really good coach or something. Having more exposure to that type of healthy people was what I always wanted and didn't always get when I was there.

I was there for seven months—longer than most of the girls—new admissions would always affect me a lot and then I would just plummet. I just had to bite the bullet and do it and that's what I did eventually but transitioning back into normal life was hard. I had to go back to school, where the last time they saw me, I was so underweight. I didn't know who knew where I'd been. There was no support system in place and living in a different city from where my treatment was made it extra-hard. I think that should've been a really happy time and it was quite the opposite. I've been a competitive dancer my whole life, so having to take that year off was extremely difficult and I had to give up ballet altogether. I felt monitored, even when I was no longer in the hospital.

Even today, people in my family will tell me I'm looking thin and need to watch myself. They see me as weird and unhealthy, no matter what I do, which is hard because that's not how I see myself. I eat completely fine now. It's almost like I'm making up for all those years. At the same time, a lot of women in my family came forward to me to tell me that they'd gone through similar things and hadn't felt comfortable talking about it. My family's very old-school so it's sometimes like mental health doesn't exist to us but I think when they saw the effect it had on me, they've been changing. As bad as it was to almost die it brought us together. I'm very lucky for that.

#### **Summary of Chapter 4**

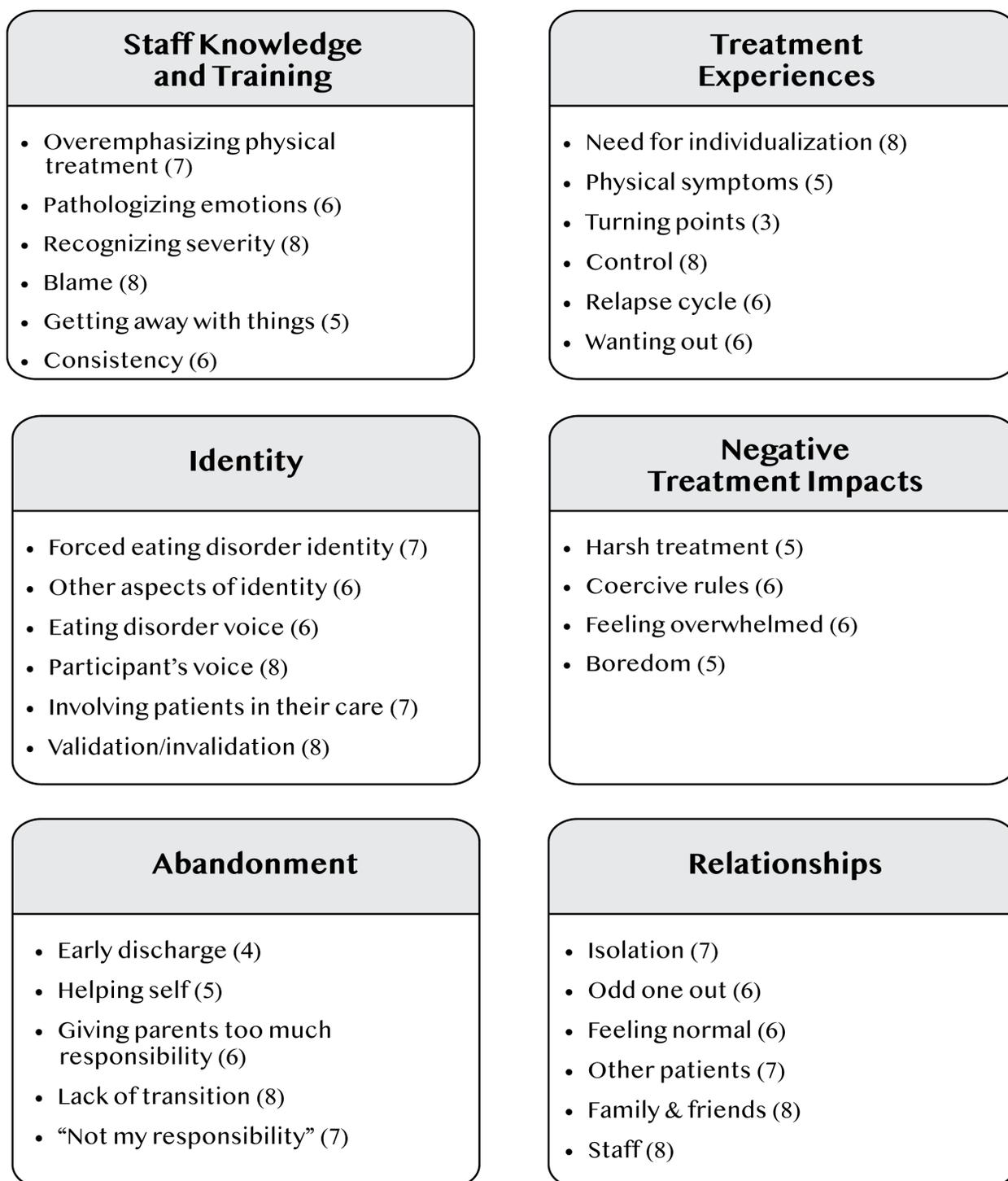
Chapter 4 presented the summarized versions of five stories that participants shared in the research interviews. Using as many of their original words as possible, I related the experiences

in the hospital that each of these young women described to me. The purpose of including these stories was two-fold: firstly, I wanted to include participants' voices as much as possible in the study, given that many of these participants shared experiences of being denied a voice in treatment. Secondly, these stories serve to highlight the divergent and varying experiences of young women who experience hospitalization from AN—something several participants identified as an important point. Having acknowledged this, I will next turn to an exploration of the themes tying these different narratives together. The following chapter will focus on some of the common elements described across participant narratives.

## Chapter 5—Data Themes and Discussion

In this chapter, I describe the themes identified across participant interviews and connect them to scholarly studies in the literature. There are six major theme clusters that were mentioned either by all or all but one participant. Within these clusters, there are also more specific themes that were mentioned by half or more of the participants. The themes are illustrated by verbatim quotes from participant interviews, which are presented *in italics*. The names of hospitals, towns, individuals, programs etc. are replaced with a descriptor in square brackets (e.g., [TOWN], [HOSPITAL]). Theme clusters and the themes that comprise them are summarized in Figure 1. The numbers in parentheses following the theme titles represent the number of participants who spoke about the corresponding theme.

Figure 1

*Theme Clusters and Themes*

## Staff Knowledge and Training

All participants described a general lack of ED knowledge among practitioners they encountered in the hospital. Salzman-Erikson and Dahlén (2017) note that knowledge about EDs is an essential element of building trust with clients. When patients encounter staff members who understand EDs, they feel less alone (Gulliksen et al., 2015). Unfortunately, the finding that staff who treat EDs lack training is very prevalent in the literature (Bezance & Holliday, 2013; Pemberton & Fox, 2011; Smith et al., 2016).

Participants frequently heard comments from staff they experienced as insensitive and felt no one knew what to do with them during their stay in the hospital. Jordana recalled, *getting to the hospital was hard because I live in (town) and especially, I find, [in] (region), people don't know much about eating disorders*. Participants wanted care from practitioners with experience and a solid understanding of EDs. This finding is consistent with previous research where AN patients wished for their treatment to be carried out by ED experts (Gulliksen, Nordbø, Espeset, Skårderud, & Holte, 2015; Rance et al., 2017). While it is unrealistic to provide specialists in every type of illness on a general ward, it is possible to at least provide staff basic training in recognizing features and symptoms of EDs.

Most participants described specific instances where practitioners made insensitive comments that reflected common misunderstandings about EDs. It should be noted that, in some research, staff also lament the lack of ED-specific training (Long et al., 2012; Reid et al., 2010); thus, practitioners' misunderstandings may reflect a lack of training availability, rather than disinterest in learning about EDs.

Participants also spoke more generally about the myths associated with AN that pervade both general consciousness and ED treatment settings. Astra said:

*That's the thing is I always try and help people understand by being like, "It's not that I sit here thinking that I'm this, like, hippopotamus"....I hate that image of the girl looking in the mirror....Every person I meet, who—when I'm trying to educate people about this, they say to me, like, "So, do you see yourself as like 300 lbs?"....You always look at, like, the flaw areas or you see areas as too much.*

Amelia noted, *the nurses and stuff, they just didn't even know where to start. Like, there's so—there were so many misconceptions.* Dimitropoulos and colleagues (2016) also address the prevalence of misconceptions in ED treatment, noting that many health practitioners believe AN is voluntary, easy to “snap out of,” that is it a shallow attempt to imitate celebrities, or that the person suffering is to blame. It is essential to address this, as Dimitropoulos et al. also found these myths and misunderstandings result in internalized stigma, which contributes to low treatment-seeking and high dropout.

In the absence of practitioners with ED expertise, many participants felt the burden of educating others about their illness fell to them. Two participants described goals of going into training settings themselves to teach about appropriate ways of speaking to people with EDs. Kate stressed the importance of knowing *what to say and what not to say. And not that you can say everything perfectly, 'cause no one does. Like, I trigger myself sometimes but it's just—there's just certain things, right? That are very, kind of, the basics.* Kate's point that no one can ever know the perfect thing to say at all times is an important one. Jordan (2017) also speaks about the *failures of empathy* that occur, even in healthy growth-fostering relationships, and notes that it is what someone does after these failures to repair the relationship that matters most.

Participants connected the lack of ED knowledge and training to a number of elements they experienced as detrimental. These themes include Overemphasizing physical treatment,

Pathologizing emotions, Recognizing severity, Blame, Getting away with things, and Consistency. Each is discussed below.

Overemphasizing physical treatment. All but two participants referenced practitioners' tendency to focus solely on physical health and weight, ignoring psychological difficulties. This finding is consistent with other studies on hospitalization for AN (e.g., Conti, 2016; Rance et al., 2017; Smith, Chouliara et al., 2016). Indeed, Norris et al. (2013) found most Canadian inpatient facilities that treat AN use physical benchmarks as the sole criteria for discharge. Participants described programs they attended as hyper-focused on weight, to the exclusion of addressing psychological suffering. Brittney explained, *basically, it was just kind of the generic...meal plan, food, and then once you're done the refeeding...cycle, then they just release you and that was it. There's no therapy to it.* Rance and colleagues' (2017) participants expressed that psychological treatment was essential to their recovery and that they would have preferred more holistic treatment, a finding echoed by participants in the present study.

Participants felt they were judged solely by whether or not they gained weight. While evidence deems it safe to restore AN clients' weight quickly (Redgrave et al., 2015; Smith, Lesser et al., 2016), studies also show this does not resolve problematic thought processes at the heart of AN (Fennig et al., 2017). Weight restored patients continue to struggle with body dissatisfaction, striving for thinness, and concerns about shape and weight (Fennig et al., 2017). Several of the present participants expressed that it was not helpful to have their freedoms and privileges restricted exclusively by whether their weight increased. Nicole recalled,

*It was just, like, all about weight, I realized....That's the only thing that they cared about....You could only get a pass if you gained weight....It wasn't about anything else. It wasn't about your attitude....It was literally only about, like, the number on the scale.*

Several participants reported that staff either implicitly or explicitly indicated that mental health was outside their area of expertise, or that they were not interested in addressing psychological symptoms. For example, Jordana said, *on [the] medical [ward], I guess, people don't really know how or want to deal with, like, mental health.* Finally, participants frequently felt that, once their acute physical symptoms resolved, staff considered them cured, even if they were still struggling emotionally. As Astra put it, *I had times where they'd say, like, you know "You're—you look healthy now. Like, why are you still here?"* Similar experiences are described in other studies of participants' experiences in ED treatment (Jenkins & Ogden, 2012; Long et al., 2012). Jenkins and Ogden's (2012) participants also felt they received support only when they appeared very ill. Their participants described weight restoration as the point at which recovery can begin, while staff tend to view it as an endpoint, seeing patients as recovered as soon as they are at a healthy weight.

Researchers warn that discharging AN patients whose weight has increased but whose psychological symptoms have not resolved is often associated with relapse (Schlegl et al., 2016; Tierney, 2008). This likely occurs because patients feel out of control as weight increases and lacking psychological support through this process strengthens the AN (Salzmann-Erikson & Dahlén, 2017). Moreover, some participants in the current study stated they felt worse psychologically once they had regained their weight if they were not given adequate emotional support. This sentiment is echoed in a study by Dimitropoulos and colleagues (2016), where patients feared no one could truly understand their psychological struggles as their weight increased. This speaks volumes to the necessity of ongoing support that focuses more holistically on recovery, rather than terminating treatment immediately upon weight restoration. It also relates to a later point participants raised: transitions back into the community following

hospitalization need to include a higher degree of support so the recovery process can continue. Thus, an emphasis on weight gain alone was experienced as a barrier to recovery.

Pathologizing emotions. Some participants described experiences where emotions they considered either reasonable reactions to their circumstances or normal parts of their ED were treated as taboo or wrong. Amelia explained:

*Because it's a young woman's disease, there's so much fear of people being antagonistic and mad and angry and that's "bad" and there needs to be so much more room to let people be angry and to scream at people and that needs to be...made okay in so many more ways.*

Conti et al. (2016) note that the tendency to punish women for expressing anger is pervasive throughout society, not only within this particular context. Emotional suppression is typically traced to having been discouraged from expressing emotions in childhood (Pemberton & Fox, 2011). Jordan (2008) describes how, when this happens, a child “disconnect[s] from his or her own experience and begins to hide or twist the experience to fit what is acceptable to the more powerful adult” (p. 96) to preserve the relationship. The repetition of this pattern is evident in patient–staff relationships in AN, where patients suppress emotions they believe will be deemed unacceptable. They tend to stifle any emotions they perceive as negative, but especially anger (Conti et al., 2016; Pemberton & Fox, 2011). Conti et al. caution that attempts at emotional suppression are ultimately unsuccessful, since emotions “remain vivid and powerful beneath efforts to block or repress them” (p. 4).

In some participants' narratives, staff discomfort with emotions resulted in a lack of support and not getting their needs met. Kate recalled how her doctor would *come in the room*

*and I'd be crying and she'd...run away. Literally, run out of the room like she was scared.* In more extreme cases, patients experienced direct harm. Mira remembered:

*A few of the girls, I know, were dealing with a lot of other psychological issues, which is, you know, very normal and that was very clearly explained to me that that was very normal but...I did once witness one girl literally be mocked in front of her face.*

Emotional avoidance is widely accepted as a key component of ED psychopathology (Lafrance Robinson et al., 2016; Mulkerrin et al., 2016; Pemberton & Fox, 2011). The relational paradigm informing the present study highlights how emotional suppression results in disconnection from others (Tantillo et al., 2013). Further, it can exacerbate AN symptoms (Kyriacou et al., 2009; Salzman-Erikson & Dahlén, 2017). Conversely, when someone identifies, names, and validates a client's emotions, they feel more supported (Pemberton & Fox, 2011; Salzman-Erikson & Dahlén, 2017). The way staff members react to a client's display of emotion determines whether they are perceived as trustworthy later on, which can impact patients' future likelihood of suppressing their feelings (Pemberton & Fox, 2011; Salzman-Erikson & Dahlén, 2017). Pemberton and Fox (2011) note that AN patients fear staff members' responses to their emotions because they worry about abandonment. Thus, it is essential that clinicians provide a safe environment where patients' feelings are welcomed, rather than confirming damaging beliefs about emotions being unacceptable.

Recognizing severity. Participants spoke to the need for practitioners to recognize the serious—even life-threatening—nature of their illness. While some of the women related experiences where their needs were recognized and taken seriously, they more often described incidents where treatment providers minimized their ED (i.e., not being admitted to the hospital, implications from staff that they were not sick enough to merit help). When participants were

taken seriously and received the support they sought, it was validating. For example, Brittney remembered a time where a doctor *admitted me on the spot, um, when she saw me. Um, 'cause my vitals were messed up again and I had lost down to my lowest weight again.* Edwards et al. (2015) note that it can be motivating when clients' symptoms are taken seriously. However, this was frequently not the case. Nicole described a long and difficult process of trying to get help for her AN. Finally, *The sixth time that...[my mom] had to call 9-1-1, I had to go to the hospital....They were like, "Okay, maybe we should admit her now."* In a similar vein, Kate warned that:

*What people need to realize,...the way our system works, by the time people with Anorexia or another eating disorder end up in an ER, they're pretty sick people....They need the help...and it's not something that they can always do on their own.*

Three participants even described instances where staff verbalized the opinion that their illness was not something to be taken seriously. Jordana recalled, *I was told, like, that because of my age that I should just grow out of it and that it should be fine.* Rance et al.'s (2017) participants describe similar experiences with practitioners minimizing the severity of their illness.

Participants are not wrong that the consequences of ignoring this illness can be dire. Physical complications of AN have the potential to be very serious and sometimes even fatal (Bakker et al., 2011; Bravender, Elkus, & Lange, 2017; Salzmann-Erikson & Dahlén, 2017). Furthermore, the risk of suicide for AN patients is high, especially among those previously hospitalized (Bakker et al., 2011; Tasaka et al., 2017; Salzmann-Erikson & Dahlén, 2017). Thus, recognizing the gravity of the situation when patients present with AN is not only helpful, it may be a matter of life and death in some cases.

One consequence of not recognizing AN's severity was that participants were not admitted to the hospital or another program that could provide more specialized care. In Canada, the first point of contact for people seeking ED treatment is usually their general practitioner (GP). Gulliksen et al. (2015) stress the importance of the first contact with health professionals for people with AN, because it can promote or prevent further help-seeking. Unfortunately, GPs rarely have the training to recognize and treat EDs (Gulliksen et al., 2015; Rance et al., 2017). General practitioners lack awareness around EDs and are frequently experienced by AN patients as condescending (Jenkins & Ogden, 2012). Half the participants in the present study reported having their symptoms dismissed by their GPs. Astra's GP told her, "*Yeah, she probably has Anorexia and she just [needs to eat].*" You know, "*Can you try taking an Ensure every day?*" Gulliksen et al. (2015) report that, when patients are not taken seriously at first contact, their motivation diminishes and they feel insignificant; conversely, they note, when professionals take patients seriously, they are more inclined to engage in treatment.

Even once the diagnosis of AN is given, participants often struggle to access needed services (Tierney, 2008). Several participants described difficulty getting admitted to the hospital, such as Kate, who:

*was sent three times to the ER and they just gave me a fluid bolus and sent me home....They're like, "Well, we can't really admit you. We don't have eating disorder services here, so, you know, just go home," and my mom was like, "What?!" Like, "You're gonna send her home with a heart rate of 30?!"...and they're like, "Well, we can't really help her."*

Nicole, too, described being sent home despite severe physical symptoms, such as:

*fainting when I woke up or, like, not wake up at all in the morning, um, and my mom would call 9-1-1 and I would go to the hosp-hospital in an ambulance. All they would really do is, like, give me an IV and then send me home, like, 4 hours later.*

In an extreme example, Astra described being unable to get on a waitlist for an inpatient program when she *was begging them and I wrote letters and I was like, "Please...I will do anything...but I actually can't gain the weight on my own."* Since ambivalence about recovery is so common in AN (e.g., Bravender et al., 2017; Long et al., 2012), most patients are unlikely to go to such lengths to advocate for themselves in seeking treatment. Thus, when young women with AN do have the strength to reach out—even tentatively—for help, it is essential that help be available.

Participants reported getting the sense from certain practitioners that their health was not sufficiently compromised to warrant a bed in the hospital. Sometimes this impression was given through comments made to participants, while at other times it was conveyed through the manner in which their care was approached (i.e., quickly abandoning attempts to convince participants to eat). Some participants reported that this strengthened the voice of the ED (see p. 97), which also repeatedly told them they were "not sick enough" to deserve help. Amelia remembered being told by a doctor that she *didn't seem severe at all [and] was probably going to go home and be okay by a couple months*. She said, *you shouldn't be judging people's severity levels and then verbally vocalizing them in front of them*. On occasions where practitioners did convey recognition that the illness was severe enough to warrant treatment, participants found this helpful. Kate described a positive interaction during one of her hospitalizations where:

*The social worker would come in and be like, "No, you need to tell her she has to finish it, like, in at least 30 minutes, and you're going to check and you're going to write down whether or not she's had it. Like, it needs to be documented such that it's seen as*

*important,” because [otherwise] the eating disorder mind comes in. It’s like, “Oh, obviously you’re not that sick. If you were really sick, they would care whether or not you had it.”*

Participants in Rance and colleagues’ (2017) study echoed the current participants’ sentiment that it was difficult to convince treatment providers they needed help when they were not acutely ill. They report that this dismissal increases competition among patients and the drive to make themselves sicker to feel like they merit the diagnosis of AN. Therefore, staff must recognize that participants’ health can still be significantly at risk and they are often still suffering psychologically, even when their outward appearance suggests normal health.

Blame. Most participants experienced incidents where they felt either overtly or covertly blamed for their AN symptoms. With this sense of blame, participants also described an impression that people were angry at them for things that felt beyond their control, leaving them feeling guilty and helpless. Reas et al. (2017) explain that, even in today’s world, “individuals with eating disorders [are] viewed by society at large as attention-seeking, blameworthy, or as having a trivial self-imposed problem and viewed by professionals as vain, manipulative or difficult” (p. 22). Blame is common, even from professionals who treat EDs (Pemberton & Fox, 2011; Reas, Gulliksen, & Isomaa, 2017; Salzmann-Erikson & Dahlén, 2017). Certainly, this was the view espoused by the current participants, such as Amelia, who stated:

*There was a lot of blame and that blame has continued, too, and they would say, “Oh, I’m not blaming you...but it was really implicit, where—“well, you didn’t gain weight so you’re going to have to go to treatment”...so it was constantly putting it all on me...and when I started to disengage, it started to be, “Well, we can’t help you if you’re not willing to help yourself.”*

Amelia's point that blame is implicit is an important one, and one that is echoed both by other participants in the current study and elsewhere in the literature. For example, Tierney (2008) found that nurses in an ED program often made negative comments about food, got angry, or gave up on clients. Many researchers call attention to professionals' views that ED patients are difficult to treat and responsible for their condition (Dimitropoulos et al., 2015; Papathomas et al., 2015; Malson et al., 2004; Tierney & Fox, 2010). Holding patients responsible is especially pervasive in general wards, which are the focus of the current study, compared to ED-specific treatment centres (Tierney, 2008). This lack of understanding is reflected in Kate's recollection that, *the doctor was nice but he would kind of, like, almost make it as if, like, I was kind of, like, a burden to the system, like, that was taking up a bed*. Tierney found that staff sometimes saw patients as manipulative or wasting resources, while Ramjan and Gill (2012) found that nurses in their study described AN patients as deviant and needing reintegration into society. Reas et al. (2017) caution that such stigmatization of patients is associated with depression, poor self-esteem, and unwillingness to seek help. For these reasons, researchers urge professionals to make it clear their conflict is with the AN and not with the patient (Bakker et al., 2011; Salzmann-Erikson & Dahlén, 2017).

Another unsettling outcome of blaming patients for their AN is that it can impact professional judgment about who will receive services. Astra explained that she was denied services because *they look at your track record. They pull up your track record and they go, "Well it looks like you did this and you discharged yourself early here."* A final aspect of being blamed that participants emphasized was the mistaken belief that AN is a choice. Eleni recalls thinking, *"I don't think you quite understand.... You don't have a choice to necessarily get [Anorexia]".... They felt that due—with the help of one's environment, um, it could be avoided.*

Similarly, Jordana expressed frustration that, *it was just choice, choice, choice. That's, like, all I heard from anyone in my life, those three months...that, um, everything I was doing was a choice.*

McNamara and Parsons' (2016) research also indicates that participants received the impression from others that their illness was a choice they were making. Education about the causes of AN, including that patients are not to blame for being sick, could have far-reaching benefits, in that it could result in more people with AN getting the professional help they need.

Getting away with things. The lack of ED-specific training often led to instances where participants got away with ED behaviours because staff did not know what to look for. Participants clearly identified this as a barrier to recovery and something they experienced as predominantly negative. This is an important point; research repeatedly describes AN patients as resistant to receiving treatment and reluctant to give up their disorder (e.g., McNamara & Parsons, 2016; Tierney, 2008). AN is frequently described as an *egosyntonic* disorder, that is something consistent with their values, which they wish to preserve (Bravender et al., 2016; Sciolli, 2016; Zugai et al., 2013). Thus, this expressed desire for containment and symptom interruption is noteworthy. As an example, Kate recalled being ignored when she was *literally doing laps around the floor and, like, full-on exercising...Like, I don't know what they were thinking.* On occasions where staff interrupted participants' symptoms by limiting unhealthy behaviours, participants described this as helpful. This was usually only the case when a staff member had struggled with an ED herself or himself, an experience reported by 2 of the 8 participants. Astra explained:

*for them to know all these tricks of the trade—they're not going to know unless they've had an eating disorder. There was one nurse who'd had an eating disorder when she was younger, and she was the one who called me on everything because she knew.*

Professionals with an ED history recognizing subtler ED behaviours has been identified as an advantage in previous research as well (Johnston, Smethurst, & Gowers, 2005; Williams, 2011).

A related issue is that participants describe the hospital as an ideal setting to learn new ways of maintaining an ED. Previous research also addresses the issue of AN patients learning tips and tricks from one another (McNamara & Parsons, 2016; Vandereycken, 2011). Secretive behaviour is a prevalent feature of AN and patients may do things to make it look like they have eaten or like they weigh more than they do (Vandereycken, 2011). While some participants in the present study reported this contagion effect as a result of exposure to other patients, more said they got ideas from the staff or from rules they had to follow. Mira explained:

*There was so much stuff I learned about maintaining that mindset when I got there—not even from the other patients. From the doctors. They would, like, restrict me from doing something and then tell me why...and I'm like, "Well, now I want to go f\*\*\*ing do it! I'm a teenager!"*

Amelia, too, noted, *even though I wasn't exposed to other patients, which obviously would have been, um, more damaging, I still learned enough from the other staff.* In line with Vandereycken's (2011) participants, these participants disliked the worsening of their symptoms that resulted from being exposed to practices they had not imagined on their own and found this detrimental to their recovery.

Consistency. Lack of consistency in the application of rules across time was cited as stressful and detrimental to recovery. Several participants also reported struggling with inconsistency between staff members in the hospital, resulting in an unsettling sense of uncertainty regarding what they could expect from one day to the next. Low tolerance for uncertainty is a feature of AN and these patients are known to struggle with inconsistency or

unpredictability in routine (Pemberton & Fox, 2011; Smith, Chouliara, et al., 2016). Thus, researchers stress the importance of mentally preparing patients for what they can expect from hospitalization (Bakker et al., 2011; Bezance & Holliday, 2013; Olmsted et al., 2010).

Since handing over control to professionals is a stressful experience for AN clients, they may resist the structure of having rules consistently enforced but, ultimately, participants tend to find it helpful (Smith, Chouliara, et al., 2016; Rance et al., 2017). The application of rules must be consistent and firm, since lack of predictability is experienced as stressful (Zugai et al., 2013). Amelia explained this in her statement:

*They're given eating disorder protocols but they don't have the capacity to follow them and so [threats] were never followed through with and so, on the one hand, that was a relief to me because...I didn't feel as bad, but on the other hand, structure really was reassuring to me.*

Jordana also received conflicting messages, saying she was told, *"As long as you stay stable, I'll discharge you tomorrow." And then on my pass, I didn't eat, 'cause I was sick, so I thought they'd keep me longer but then they were like, "Fine, whatever," so I went home.*

Enforcing structure is essential during early phases of treatment; when nurses were "understanding but at the same time confident enough to challenge the patient, this was experienced positively and it strengthen[s] the feeling that the nurses [are] there for them" (Salzmann-Erikson & Dahlén, 2017, p. 8). Unfortunately, consistency is frequently lacking in hospital programs for AN and this causes patients anxiety (Long et al., 2012; Ramjan & Gill, 2012). Jordana described the stress of not knowing what to expect, saying, *in general, I didn't know what was happening to me. I didn't know what the rules were.* Kate suggested that, in order to alleviate this uncertainty and to validate the importance of clients' care, staff should be *on the*

*clock, documenting, like, just being professional about it...and I just felt like, you know, that kind of care wasn't—they didn't see it as important for me sometimes.* Zugai and colleagues (2013) note that, when patients know ahead of time what consequences they can expect for breaking the rules, treatment compliance increases.

The other type of continuity, which appears less often in previous research, is that of the staff members involved in clients' care. Participants found it frustrating having to re-explain their story multiple times to different practitioners. Nicole expressed this, saying *I understand a multidisciplinary team, like, in every hospital but it was really annoying, because, like, every hour a new person would come in and try to talk to me.* Also, as Kate explained, it was hard to predict how each new professional would respond, since

*every time you go in, there's that anxiety of like, "Okay, who's going to say something triggering to me? What are they going to say? Are they going to tell me to just go home? Are they just going to tell me that I'm a waste of space?"*

Furthermore, messaging was not always consistent among the different professionals, such that, as Amelia described:

*half the practitioners act[ed] like "Why are you here? This isn't an emergency. We can't help you. This isn't anything we know about, and...there's nothing we can do," and the other half of people [said], "Danger! Danger! This is so dangerous! We need to get you in"...and so it was this seesawing, back-and-forth of, kind of people checking in and then checking out.*

The impression participants gave was that the number of staff members involved in their care, as well as the inconsistency in messages conveyed by these disparate professionals, caused

similar stress to the inconsistency in program structure and rules. Since this finding has not appeared in previous research, it could be an area for future study.

### **Treatment Experiences**

There were several themes identified in the analysis that described aspects of participants' experiences in treatment. These include Individualization, Physical symptoms of AN, Turning points, Control, Relapse cycle, and Wanting out.

Need for individualization. All participants believed it would help if ED patients were treated more as individuals, with their unique needs addressed in treatment, rather than using standardized procedures that did not necessarily work for each specific person. Jenkins and Ogden (2012) report that participants describe recovery as a long and difficult journey. However, treatment tends to be rushed, ignoring the needs of the individual and lacking needed collaboration between clinicians and patients (Jenkins & Ogden, 2012). This matches the views espoused by the current participants, which Kate summarized in the statement, *everyone needs different things at different times, depending on how, you know, they're presenting, and how strong the eating disorder is at the time.*

Several participants reported others treated them based on ED stereotypes, rather than on a careful assessment of them as an individual with unique needs. Salzmann-Erikson and Dahlén (2017) suggest that when staff have to restrict patients from doing something, it should be relevant to the individual's situation, along the same lines as Brittney's suggestion that *they should assess [rules] on the patient, not just generically.* Zugai and colleagues (2013) warn that

where patients perceive rules as irrelevant, too strict, or inflexible, they also perceive treatment as punitive.

Amelia reported feeling frustrated with how assumptions made about her based on her diagnosis determined the course of her treatment, saying:

*I grew up in a household where it was a very alternative lifestyle and I didn't and never have cared about my looks and I didn't read dieting magazines and I played hockey....I never have fit into the stereotypical kind of person who would get an eating disorder.*

Along a similar line, Eleni's view of the professionals treating her was that *they really don't want to take the time to fully understand you. It's more or less, like, "Well this is what I studied. This is what I've seen so far and this is how I'm going to treat you."*

In support of participants' claim that individualization of treatment would be more helpful than treating each AN patient identically, different participants expressed starkly contrasting views on certain features of treatment. One example that came up frequently in interviews was feeding tubes and other forms of meal replacement. Among the four participants that raised this issue, views on the practice of meal replacement were evenly split. While acknowledging that there is a place for meal replacement in hospitalization, Kate and Astra both spoke about how it reinforced the ED mindset and expressed a preference for eating "normal" food. Astra stated:

*I also don't like what's in, like, Ensure and that sort of stuff. Again, I don't look at it as that much of, like, a health thing....I mean, even myself right now, I go, "Would I rather have an Ensure or, like, a smoothie? I'd rather have a smoothie." You know? Real food.*

On the other hand, Nicole and Jordana recalled being at a point in their illness where voluntarily eating regular food was not an acceptable option to them, where using meal

replacement was the only way to get any nutrition into their bodies. Nicole's view of the issue was that:

*They just let me sit in front of my food until the 30 minutes was up and then put 3–4*

*Ensures into my tube. It was torture if you ask me, because they should have just not let me*

*sit in front of the food and just went straight for the Ensure route.*

Previous research has stressed the impossibility of creating one mealtime protocol appropriate for every client with AN (Long et al., 2012). The participants' sharply divergent views on an issue affecting nearly every hospitalized AN client reinforces this vital point. While learning about the needs and preferences of each client can be a time-consuming process and difficult to implement in a busy hospital, Bryson et al. (2017) argue that doing so can be tremendously powerful. This is supported by the current participants' positive descriptions of times staff did modify treatment protocols to meet their individual needs. Amelia recalled a time where her nurse *totally adapted [a hospital policy]...and, like, those small ways that they tried to make things better for me were, like, such a relief*. Zugai et al. (2013) similarly identify that when staff adapt the rules to individual clients, their relationship is more favourable.

Although some characteristics are common in patients with AN, it is essential for treatment providers to avoid assuming their patients will behave in a certain way based exclusively on their diagnosis. Participants overwhelmingly indicated that being treated as individuals would have made their stay in the hospital more effective and comfortable.

Physical symptoms. Many participants talked about physical symptoms they experienced; for the most part, they described treatment of these symptoms as a strength of the hospital programs. Astra acknowledged, *the hospital does serve its purpose with giving you the aides for, like, digestion and, you know, going to the bathroom and all these things that you can't really get*

at home. When participants experienced severe physical symptoms, they were more likely to be taken seriously, as Jordana was when *they tried to fast track me because of my, like, heart rate and stuff, 'cause it was, like, really low*. Kate recalled how, once she was admitted to the hospital, her physical symptoms resolved quickly, saying:

*My bloodwork came back fine. Um, you know, once I got re-fed a little bit, my blood pressure—and got IVs and fluid—over a couple—a few days, my blood pressure started to come up,...my heart rate started to improve. These things started to improve.*

Due to the high medical risk in AN, resolving physical complications (such as low heart rate) and achieving weight restoration are essential treatment goals of hospitalization (Makhzoumi et al., 2017). Therefore, it is encouraging that most participants felt their physical symptoms were effectively dealt with.

Turning points. A few participants described turning points as part of their narratives, where their mindset shifted and they became more open to the possibility of recovery from their ED. Sometimes this was linked with external motivators, such as when Brittney said:

*I think it was coming to the point where I **was** sick enough, and I realized that I was sick enough and that I'm an adult now and, like, that I want to be a police officer. I want to be a paramedic and these things will be happening to me in the next 12 months.*

Others, like Astra, described turning points related to internal factors:

*Where I'm at right now mentally is a different place than I've ever been and it's a place where, like, I'm actually not trying to get sicker and I'm not trying to play this game anymore....I really want to get better for once and I'm wholly committed.*

Smith, Chouliara et al. (2016) describe such turning points as empowering, pointing out that when patients reach a point where they are—due to internal or external motivators—able to

regain control over their eating, this can result in the confidence shift implied in Astra's comment.

Control. Several participants brought up the importance of control as a central feature of their ED. Eleni explained that her *main focus was never to be thin....The whole concept for me is just having, um, like, this OCD type of need to want to control everything in my life....I think it's just this requirement to feel safe.* Researchers characterize ED behaviours as a means of asserting control over a life that feels chaotic and gaining a sense of mastery or achievement (Jenkins & Ogden, 2012; Smith, Chouliara et al., 2016). Participants described difficulty relinquishing control during their stay in the hospital, especially when they got into conflict with hospital staff, as Brittney expressed when she said:

*I knew I needed to try better but I still was needing the control of it, 'cause they took everything away when I got out, so it was more stressful for me....They took my scale and stuff, so they were taking that control away from me still.*

Nicole simply said, *I felt very powerless and in jail.* Interestingly, similar prison metaphors are pervasive in the AN literature (Pemberton & Fox, 2011; Ramjan & Gill, 2012; Vandereycken, 2011). Power struggles between hospitalized AN patients and staff are not uncommon, particularly at mealtimes (Long et al., 2012). These can lead to a lack of trust between staff and patients (Pemberton & Fox, 2011). Sheridan and McArdle (2015) found that a controlling environment is linked to poor emotional and symptom outcomes.

Kendall (2013) notes that the behaviour of patients with EDs often reflects a need for control and that, when these patients feel others are exerting control over them, it can impact their ability to “make autonomous, balanced treatment decisions” (p. 37). Jordana described how lack of control decreased her motivation since *when I did start trying, they didn't really care, it*

*seemed like, because they didn't do anything different. So it seemed like it didn't really matter what I did.* Along a similar line, Salzmann-Erikson & Dahlén (2017) assert that the feeling that treatment is “being done to” patients is aversive, prompts resistance, destroys the therapeutic relationship, and strengthens the AN.

At the same time, most participants acknowledged times when they needed staff to take control so the ED would not consume them entirely. Kate said:

*At that point, usually I was desperate for someone, like, just to, like, take responsibility from me....I'm so, like, done with having to, you know, fight against my brain. Someone just tell me what to do. Like, **tell me.***

Tierney (2008) described similar experiences among her participants, who felt relief and an easing of their guilt when forced to eat and discontinue exercising, because these were not decisions they themselves were making. Rance and colleagues (2017) also refer to the complex dynamic of patients simultaneously wanting and not wanting control. While handing over control can be a positive step in some clients' recovery, it can simultaneously create significant anxiety (Smith, Chouliara et al., 2016; Salzmann-Erikson & Dahlén, 2017). Conversely, having too much choice and control often results in a worsening of AN symptoms (Smith, Chouliara et al., 2016). Nicole recognized this, yet expressed that some degree of control would have made her feel less powerless. She acknowledged, *too many options would've been worse. Like, if they said, "Okay here's a menu of, like, 25 things. You can pick what you want." But it was like, even...if I got to choose between two things.* Smith, Chouliara et al. (2016) also acknowledge that being able to regain some control as treatment progresses is empowering for hospitalized clients. Similarly, Jenkins and Ogden (2012) note that, as patients regain control over the AN's voice, it loses its power over them. Researchers recommend that any return of control to a patient be done

gradually, with increasing opportunities to make choices about food; if they struggle, returning to a more directional approach is indicated (Bakker et al., 2011; Salzmänn-Erikson & Dahlén, 2017).

Control is a complex and challenging aspect of ED treatment; practitioners must work to find a balance between providing sufficient structure to keep AN from controlling clients' actions, while also allowing patients enough autonomy to keep them engaged in treatment.

Relapse cycle. Most participants described at least one ED relapse in their narrative. Relapse rates are high in this population, partly due to lack of preparation and support during the transition back to the community (Ramjan & Gill, 2012). Patients most at risk for relapse are those whose weight increases but have no change in psychological symptoms (Schlegl et al., 2016).

For some participants, relapses occurred within a relatively short time span, while others had a series of relapses and admissions that spanned several years. Some spoke about not feeling motivated to get better and began anticipating their relapse while still in the hospital. For example, Nicole recalled, *my whole mindset the whole time I was inpatient was all like, "As soon as I'm going to get out of here, I'm going to lose more weight."* Similarly, Astra described that *I got a lot of out of it, but I also was just not ready to get better and the day I left, I was just on relapse mode...and within three weeks, I was back in [HOSPITAL].* Jenkins and Ogden (2012) make the critical point that psychological treatment is only as effective as the client's level of motivation; an unmotivated client will simply relapse immediately following release, as these participants did.

Several participants reported a long and tiring ordeal with treatment and relapse that left them exhausted and frustrated. Brittney said, *every time I go into the hospital, I always think I'm*

*going to get better this time. I'm going to get better this time, and for the first four years of that, it was very hard for me.* Kate related a long and repetitive cycle as well, where:

*[I] was admitted to a eating disorders program...lasted 3 months, weight restored and then started relapsing again, while I was in [the program] and so I left and relapsed pretty much right away...so I got out of there in July and—no. Yeah. End of July and I was sent back to the hospital by [OUTPATIENT PROGRAM] in November.*

Researchers note that a relapse prevention plan is critical as patients prepare to transition back to the community (Bakker et al., 2011). Khalsa and colleagues (2017) suggest that, since the highest risk of relapse is in the first year—and particularly within the first three months—following release, patients should be reassessed at least every three months for the first year. Few accurate predictors of relapse have been established; thus, individualized follow-up is essential (Khalsa et al., 2017). Since Conti et al. (2016) note that those who do not recover from AN within the first seven years are unlikely ever to recover, these long cycles of relapse and recovery should be avoided at all costs.

Wanting out. Most participants reported that their primary focus during their admission was to be discharged from the hospital and be allowed to return home. In many cases, this resulted in a mentality where participants felt they were “going through the motions” to get released as quickly as possible, with little regard for their long-term recovery. Kate explained that *I kind of got into the mode, “Well, okay fine, I’ll prove to them—like, I’ll just eat” and then...got out and then relapsed really badly.* Participants described quickly learning what they needed to do to get out of the hospital, as Eleni did when she *learned that I just had to listen to them. I had to keep my mouth shut and just get out, which is what I did.* In some cases, participants felt the unpleasantness of the hospital environment temporarily outweighed their fear

of weight gain, such that they were able to improve just enough to be released. Nicole explained, *because it was like jail for me, I was trying to...be off my form so I could go home*. In all of these stories, the participants seemingly had no intention of recovering from their ED; they merely saw compliance with the hospital's rules as the only way to achieve the freedom they needed to pursue other goals. Astra said, *the minute I was uncertified, I discharged myself. I wanted to go back to school*. Kendall (2013) cautions that the current practice of rewarding patients for accepting hospital rules and treating compliance as progress can be problematic. They warn that obedience can reflect a desire to please staff or a sense that they have no other choice, as opposed to actual improvement. Long et al. (2012) found that AN patients felt their views were disregarded and they had no choice but to follow the prescribed program (Long et al., 2012).

### **Identity**

A large portion of participants' accounts focused on aspects of their identity. Identity is cited as a central concern in ED pathology and recovery in a large body of previous research (e.g., Bravender et al., 2017; McNamara & Parsons, 2016; Williams et al., 2016). Since the typical adolescent age of onset for AN coincides with a key period in identity development, it is perhaps unsurprising that struggling with identity tends to precede and possibly contribute to the emergence of AN (Salzmann-Erikson & Dahlén, 2017; Williams et al., 2016). A key concern in ED treatment is that clients' identities tend to become entangled with the ED (Kendall, 2013; Tierney & Fox, 2010; Williams et al., 2016), such that they fear a loss of identity if they pursue recovery (McNamara & Parsons, 2016). When speaking about their experiences in the hospital, participants' discussion of their identity fell into five smaller theme areas: Forced eating disorder identity, (Re)connecting to other parts of their identity, Eating disorder voice, and Participant's authentic voice.

Forced eating disorder identity. Many participants gave accounts of others projecting ideas onto them about how someone with an ED should behave and then treating them accordingly. For example, Kate recalled, *it was tough, because, like, I was a very shy obedient child and when I went in, they started treating me as if I was some like really super-rebellious, like, really evil [person]*. Research shows practitioners endorse certain stereotypical expectations about AN that can lead to incorrect assumptions and prevent them recognizing clients' individual qualities (Bravender et al., 2016; Jenkins & Ogden, 2012; Smith, Chouliara et al., 2016).

In some cases, participants believed others could not separate them from their illness; thus, they were treated as though they “were” the ED. Astra commented that, *the minute you walk through, like, any doors or whatever, you are this disorder. You lose your identity and therefore that identity becomes the eating disorder*. When people treat AN patients as inseparable from their ED, this further compromises their already vulnerable identities (Bezance & Holliday, 2013; Salzman-Erikson & Dahlén, 2017; Williams et al., 2016). Additionally, when people equate the person with the ED, their identity as a sick person is strengthened, making it more difficult to imagine recovery (Kendall, 2013; Malson et al., 2004). Indeed, by imposing their expectations onto patients, some participants thought staff members were, in a way, reinforcing their ED. Amelia explained:

*It wasn't necessarily—at least, as I felt then—particularly a specific presentation of an eating disorder and then it was constantly being defined so much in those terms that I felt they were making it become an eating disorder. I even said that to my dad. I said if they just hadn't named it, I could maybe have gotten over it in a couple months, which obviously wasn't the case but that was my feeling of it at that time.*

Some participants also described how others' view of them as sick people impacted their ability to maintain recovery following their release from the hospital. These incidents primarily involved other people in participants' lives, rather than ED practitioners. For example, Mira remembered her *aunt would call me over and she'd be like, "Hey, I saw you running past my house. I want you to, um, know that you're looking very thin and that you need to, like, watch yourself."* Similarly, Astra described an experience with friends where *they were commenting on what I was eating and, "Is that enough?" and... "How much are you exercising, (Astra)?"* In both these cases, the women found being unable to escape the AN identity following hospitalization made it harder to identify as recovered. Dimitropoulos and Freeman (2016) identify that families' anxiety about the ED is a factor that can impact a successful recovery. Therefore, having others communicate confidence in clients' ability to maintain recovery may help AN patients remain healthy after their time in the hospital.

A few participants spoke about how practitioners defined recovery from the ED for them in a way that did not match with their hopes for their future. Astra found it difficult to remain optimistic about recovery when receiving the message from staff, *"you'll struggle for the rest of your life, and...essentially, you'll be fat, but you'll still struggle for the rest of your life"....I'm going, "Yeah. Right. That's worth it, then."* Rance et al.'s (2017) participants also reported being discouraged by practitioners' suggestion that full recovery was impossible. Conversely, Amelia spoke to the importance of meeting patients where they are at when they, themselves, feel achieving recovery is unrealistic. She said:

*If somebody is saying, "I will not recover. I am not going to be in recovery,"...then you don't keep using the language of recovery and the language of how beautiful someone's*

*life is going to be in 5 years. You say, “Okay. Right now, we need to get you to a medically stable place, that’s just basic.”*

Research shows professionals’ definitions of recovery rarely align with clients’ definitions (Conti, 2016). Jenkins and Ogden (2012) argue recovery is an individualized construct, specific to each person struggling with AN. Many participants felt that clinging to a definition of recovery based on an ultimately unattainable pre-disorder definition of “normal” slowed their recovery (McNamara & Parsons; Williams et al., 2016). Some reach the conclusion that full recovery may not be possible but that there are things they can do to manage their illness and make their lives better in spite of this, defined by Papatomas et al. (2015) as the *survivor model of recovery*. This was the case for Eleni, who concluded, *I don’t think it’s necessarily recovery. I think it’s more like how you manage it and live your life....I’ve got everything else under control, but um, there’s just—I’m not moving past a certain level in my life anymore*. For these reasons, it is imperative that professionals listen to the person struggling to learn what recovery means to them, rather than assuming they understand based on previous clinical experience.

Other aspects of identity. It is often suggested that connecting to new or forgotten parts of one’s identity outside of food and weight is a factor in ED recovery (Conti, 2016; Papatomas et al., 2015). Many participants described the role of other parts of their identity outside of the ED. Some explained how they reconnected to those parts of themselves in a healing way; however, many also talked about how being in the hospital stripped away other parts of their identity,

leaving them with nothing but the ED. Eleni described missing things while she was in the hospital that had made life feel worthwhile:

*You were totally alone with your own thoughts and your only hope was to get out, to see something, you know? Like, to breathe. Get fresh air, you know, to experience life in a more pleasant way, but it—nothing was pleasant about the whole, uh, thing.*

Jenkins and Ogden (2012) describe how an AN-based identity is narrowly focused on one part of the self (one's body), while a recovered identity contains many different elements. This narrow and rigid appearance-based identity thrives once other parts of the self are stripped away in treatment. Mira explained, *I've been a competitive dancer my whole life, so having to take that year off was extremely difficult for me....It's hard for everyone, having to put your life on hold like that.* Putting one's life on hold is described elsewhere as difficult for patients too and research indicates transitioning home is more challenging as a result (Edwards et al., 2015). Amelia suggested opportunities to stay in touch with other meaningful parts of her life while hospitalized could have helped her cope, saying *maybe I wasn't able to ride but if they had been able to keep me connected to horses, for example, that might have really supported me in the long term.* Edwards and colleagues (2015) suggest patients should be able to continue life as usual to the extent possible in the hospital environment.

Sometimes, discovering new passions with which to identify can help patients move beyond defining themselves exclusively by their AN. Astra recounted stories she heard from recovered individuals about finding other experiences more worthwhile than their ED:

*From what I've heard from so many people is that once they got—like, they hovered around kind of that minimum...for a year or two and then they just slowly started getting*

*there on their own, because they realized...“I want to go hiking. I want to go do these things,” and then their body just started going there.*

Discovering previously unexplored facets of one’s identity in this way improves confidence for people in recovery from an ED (Smith, Chouliara et al., 2016; Williams et al., 2016). Conti et al. (2016) conceptualize this period of discovery as one of finding connection, whether that is with other people, something spiritual, one’s environment, or meaningful activities. Discovering or rediscovering hidden parts of the self can be challenging, because it involves risk and vulnerability (Williams et al., 2016). It necessitates the abandonment of a sick person identity—which some patients have held for a long time—in favour of a recovered identity (McNamara & Parsons, 2016). Hospitals could help with this by providing a safe environment in which to explore other parts of the self.

Eating disorder voice. The theme of voice appeared in most participants’ accounts of their time in the hospital. The two main voices discussed were the voice of the ED and the voice of the client’s authentic, healthy self.

Several participants spoke about their ED in a personified manner, describing it as a separate entity with desires, rules, and characteristics distinct from those of the participant. The ED is usually positioned as the irrational or emotional side of the self, overpowering the participant’s logical side (Williams et al., 2016). Astra highlighted the contrasting views of her ED and what she objectively knew to be true, when she said, *you always look at, like, the flaw areas or you see areas as too much, but it's always—it's just because it's too much for your eating disorder.* Several participants described the ED voice as though it had its own wants outside of their own, such as when Brittney said, *I told myself I'd get down to whatever obscure weight that my eating disorder wanted to.* Participants with EDs tend to describe interactions

with their ED voice as a struggle or a battle (Conti et al., 2016; Tierney & Fox, 2010). Kate said, *I'm actually a rule follower....I respect authority. I like to follow rules but my eating disorder makes it such that I can't, sometimes. It's just so loud. It's so overpowering.* The theme of the ED voice as a powerful influence over the person's actions also appears in Tierney and Fox's (2010) findings. This idea that the ED is an overwhelming adversary to be conquered tends to pervade popular treatment modalities and can make it more difficult to recover, since EDs fight back harder when approached in this manner (Conti et al., 2016). Overall, participants experienced the voice of the ED as a powerful force they had to contend with every day and of which they wanted professionals involved in their care to be aware.

Participant's voice. Many participants also described times they were aware of their own voice expressing their authentic needs. For example, Brittney recognized the presence of her healthy self when, *[the doctor] wanted to admit me and...I was nervous but I wanted to....I didn't know anything about it but I knew in my head that that's what I needed.* Contrary to what is often suggested in the literature, namely that an ED entirely takes over one's identity (e.g. Kendall, 2013, Tierney & Fox, 2010), participants could distinguish between what they needed to be healthy and what their ED was telling them. However, because their behaviour did not always reflect this awareness, participants perceived *so often that people with eating disorders' voices are discounted because... "It's your eating disorder."* (Astra). The finding that participants' voices are discounted because of AN is common in the literature (Malson et al., 2004; O'Shaughnessy et al., 2013; Smith, Chouliara et al., 2016). Kendall (2013) notes that a diagnosis of AN is often enough for patients to be declared incompetent to make any treatment decisions. Some participants talked about how the perception that the ED distorted their thinking prevented

them from having a say in the direction of their treatment that could have helped them get things they needed to recover. Mira commented:

*Improvements needed to be made and given that we were in there as, you know, psych patients, the kind of changes we wanted to see were just taken as, you know, skewed reality,...as though, like, any sort of conscious reasoning was just completely out of the picture. That was completely impossible.*

Amelia found it incredibly painful when her *experiences either were never expressed, or I had to translate them into something that felt inauthentic to me, in order for them to be heard*. Some participants described disturbing instances where they were actively denied a voice in treatment. Jordana said, *they just started, like, drugging me up....They just started giving me drugs that, like, really calmed me down and made everything confusing*. Other participants described specific examples of interactions where staff dismissed them and interpreted their beliefs as wrong because they had AN. Nicole argued that her veganism *was definitely an ethical thing, um, because I'm still vegan but, at the time, all the doctors thought that it was, like, an eating disorder thing*.

Participants acknowledged that the influence of their ED voice was often strong throughout their hospitalization but still found it difficult when others automatically assumed the ED controlled everything they thought and said. Astra summed up the nuanced coexistence between the two voices beautifully:

*Even though my eating disorder has, for a long time, been the forefront of a lot of conversations, I've always been there. Like, my voice is always there and it may not have ever...come out, but I always knew when I was doing something wrong....I knew what I was*

*doing was stupid and, even though I may look at myself and see myself as, like, bigger than I actually am, I am logical enough to know that the number on the scale isn't healthy.*

Pemberton and Fox (2011) also discuss how treatment providers may struggle to differentiate behaviours controlled by the ED from individual personality traits. Eleni suggested treatment experiences might be improved *if a child [with AN] was, I don't know, vegan or vegetarian or, you know, just did not like the taste of x, y, and z, you know, try and work with the kid.* Similarly, Amelia proposed a solution where *somebody...will listen and will say my needs, whatever they are, and they might not always be followed but they need to be at least vocalized.* Research by Bryson and colleagues (2017) suggests hearing the needs and priorities of psychiatric patients can have huge impacts on treatment satisfaction and success. Thus, patients feel much more could be done to make them feel heard in treatment and this could have significant repercussions in terms of improving treatment outcomes.

With the constant presence of two opposing voices in their minds, it is hardly surprising that participants made frequent references to feeling torn between them. People with AN typically struggle between wanting to get better and wanting to hold on to their ED out of a sense of comfort or a fear of recovery and weight gain (Tierney & Fox, 2010). Ambivalence is an almost universal experience for those recovering from AN (Bravender et al., 2017; Jenkins & Ogden, 2012; Long et al., 2012; Williams et al., 2016; Vandereycken, 2011). Sometimes, the participant's voice remains in the background, while the ED retains control over their actions, as Kate explained when she stated:

*I was thankful that, like, the doctor and social worker, like, you know, did what they did and worked so hard, even though I was fighting against it and didn't want it the whole time. You know, 'cause it's like, you do want help but you don't want help, right?*

Rance and colleagues (2017) note that it is common for patients with AN to both want and fear control, leading to behavioural displays of resistance while part of them remains committed to getting better. It is common for patients to appreciate the help they received after the fact, as Kate described (Bravender et al., 2017; Van Ommen et al., 2009; Zugai et al., 2013).

Eleni described the opposite pattern, where the ED maintained a firm stronghold within her thoughts, while her actions reflected those of someone striving towards recovery. She said, *that was just going through the motions every day. Like, I had no concept of whether I wanted to get better, whether I wanted to get worse. Like, I was just trying to, uh, find a middle ground.* Some participants, like Astra, described the ambivalence as exhausting, making it easier just to give in to the ED, rather than being always at war with oneself. She explained, *I still never, you know, fully wanted it, um, but I'm also, like, getting so tired of this.* Long and colleagues (2012) explain that, in cases where behavioural change is evident but the ED mindset remains, patients may perceive that they have no control over their situation and have no choice but to feign commitment to recovery. Olmsted et al. (2010) note that staff must remember many patients are not fully motivated, even if they voluntarily accepted to be admitted. Since ambivalence is part of nearly every AN patient's experience, staff need to recognize this internal conflict and not assume, if patients appear resistant to treatment, that this indicates a total lack of motivation.

Involving patients in their care. One of the ways participants' voices were either discounted or respected was the amount of communication they received and input they were permitted regarding their care. Some participants spoke about their appreciation for staff members who made an effort to include them in conversations about their treatment, while many also spoke about being left out of the dialogue about their care. Brittney said, *my social worker*

*was really good. They kind of walked me through it.* On the other hand, Amelia recalled being left in the dark, where:

*[the hospital was] in contact with [SPECIALIZED INPATIENT PROGRAM] at that point but they weren't telling me at that point. It was all kept from me....I was woken up one morning at 4 AM and they just told me, "You're going."*

Some of the women also identified a need for more extensive communication among team members to coordinate treatment efforts. Jordana suggested that *they should've communicated with each other and with me. Even doctor to doctor, they didn't know what was going on.* Researchers stress the need for some degree of collaboration between patients and treatment teams (Bezance & Holliday, 2013; Geller et al., 2016; Jenkins & Ogden, 2012). Sheridan and McArdle (2015) studied a model where treatment was collaboratively planned and found positive outcomes. This cannot occur, however, if patients are kept in the dark about their treatment.

Some participants described instances where staff communicated exclusively with their parents, while others' parents were left out as well. Eleni said, *they explained it to my mother. They didn't say it to me but my mother gave me the information.* Similarly, Jordana explained, *they only talked to my parents and not to me, and my parents weren't telling me what was going on either, so I really had no clue.* In other cases, parents too were left out of important conversations about participants' treatment. Kate recalled, *when I went in, um, you know, my family we didn't really know what was going on....Like, my parents knew I had an eating disorder—Anorexia—but we didn't really know how it was treated or anything.* This was commonly described at the beginning of participants' admissions, but also sometimes continued throughout their time in the hospital. Nicole said, *[My mom] wasn't, like, told anything...when I was, like, in the hospital. Like, she would sit with me sometimes during meals, but...they didn't,*

*like, tell her anything...any tips or anything.* On the other hand, Mira expressed appreciation for staff members who *were very good about, you know, talking to our parents with us rather than about us.* Parent relationships with treatment providers are important if they are to effectively support their children following discharge (Bakker et al., 2011; Salzmann-Erikson & Dahlén, 2017). Van Ommen et al. (2009) suggest inviting parents into the treatment environment to see how staff handle mealtimes; this can help them provide a more supportive environment at home. Similarly, Edwards and colleagues (2015) note that parental involvement throughout hospitalization is crucial and more opportunities for this are needed. Empowering parents to take a larger supportive role in their child's treatment is one possibility for supporting patients' long-term recovery.

Validation/invalidation. Participants cited the powerful impact of feeling heard by other people, as well as the detrimental effect of feeling their experiences were invalidated. When Astra spoke about her therapist, she stated, *she was very validating and made me feel a lot better about it and just said how normal [ED BEHAVIOUR] is.* Mira talked about the benefits of visits from people from outside the hospital who had also struggled with EDs, saying *[my dad] would, like, you know, bring them with him to [HOSPITAL] to come and chat with me and, like, you know, have conversations girl-to-girl, be like, you know, "I'm allowed to feel validated."*

Sadly, participants also described instances where they felt deeply invalidated. This was related to a perception that their illness was minimized or that they were a waste of practitioners' time. Amelia said:

*It was really invalidating, because here I was, totally not able to cope and everybody freaking out and then being told that, "Not only are you not...that bad but we can even compare you to other people and say that they're **really** bad and you're not at all."*

It has been shown in other studies that AN participants often feel their suffering is trivialized (Long et al., 2012). When participants felt invalidated, it tended to result in distrust and disengagement. For example, Eleni's view was that, *I find that I have found more strength in myself than listening to professionals, because they really don't want to take the time to fully understand you*. Her view is in line with Smith, Chouliara and colleagues' (2016) finding that when participants feel invalidated it is difficult for them to engage in treatment.

### **Negative Treatment Impact**

The participants described a number of negative impacts of the treatment they received in the hospital. Hospital practices aimed at changing participants' behaviour frequently resulted in conflict with staff or drove participants to disengage from treatment. The themes in this cluster include Harsh treatment, Coercive rules, Boredom, and Feeling overwhelmed.

Harsh treatment. Many instances of negative impacts involved harsh treatment by staff, such as physical force, being heavily medicated, and having their belongings confiscated. Amelia recalled a frightening incident, where she:

*tried to bolt out of the room and it was a nightmare. Like, they ended up restraining me.*

*They restrained me on a stretcher, where they got restraints and they tied down my wrists and my legs to the stretcher and they injected me with a sedative.*

Jordana recalled, *I ended up drinking [a meal supplement] because [LAUGHING] they drugged me again....Now that I think of it, I guess that's how they got me through those two admissions was just by drugging me*. Brittney and Mira also described a fear of being restrained or tranquilized if they resisted against staff. Brittney said, *I knew that if I fought them more on it, like if I ripped it out...that I would get restrained to the bed and that that would be, um, worse*. Mira said:

*[People were tranquilized] all the time, 'cause people would try to, you know, escape, right? [SARCASTICALLY] And, of course, the best way to deal with an 80 lb girl on the loose is by tranquilizing her 'cause she's a very dangerous person.*

Bryson et al. (2017) argue that universal practices in hospital environments intended to prevent harm, such as restraining psychiatric patients, have no evidence base and can result in greater harm. They note that patients have described the impact of such practices as “a loss of self-respect and dignity and in feeling less safe” (p. 12).

In some instances, participants described feeling treated as less than human by staff. Mira said, *I mean, like, just the sheer, like, dehumanization....[They treated us like] cattle.* Eleni described severe isolation she experienced, saying, *they wanted to limit any, um, influence, which I understood, but at the same time, I was looking at them and I'm thinking, "this is not how you treat a human being."* Jordana recalled that, *there was some nurses who thought it was funny that I knew the calories in everything so they would, like, test me.*

Another practice participants often described as harsh was the use of a nasogastric feeding tube (NG tube). Bezance and Holliday (2013) found that AN patients saw the NG tube as a punishment and a frequent focus of struggles for control with staff. Kate recalled:

*I was NG-tubed. Um, I was in pain. Like, I don't know what was wrong with that NG tube but I was in a lot of pain so I was, like, screaming and crying to get it out 'cause, like, I was in so much physical pain, like, in my throat. Like, it was inhumane.*

Developing and preserving a strong and trusting therapeutic relationship requires avoiding this type of harsh treatment. Bryson et al. (2017) studied inpatient psychiatric programs that took steps towards eliminating similar practices and found many had successful outcomes. Given the

importance of patient–staff relationships that will be discussed later in this chapter, practices that undermine patients’ trust and make them feel dehumanized should be avoided.

Coercive rules. Participants described coercive rules, where the amount of kindness and compassion or privileges they received were contingent on compliance with hospital rules or treatment plans. Amelia recalled that:

*Kindness was held out as a carrot. It was kind of like, “We’ll be nice to you, but first you have to eat your dinner and we will support you and listen to you and give you passes, but first you have to be compliant,”...and that’s so not okay.*

Mira’s experience was similar. She said:

*They were so quick to take away privileges, I found. Like, things like being able to go on a walk...was used as leverage to make us eat, which I think was pretty f\*\*\*ed up, personally. At least, that’s not the way I would go about it.*

This type of punitive system is prevalent in ED inpatient environments (Ramjan & Gill, 2012; Sheridan & McArdle, 2015). Salzmann-Erikson and Dahlén (2017) note that this is more common where AN-specific training is lacking. Coercive treatment does not help AN clients; guidance, rather than coercion, is essential and treatment goals need to be mutually agreed-upon to be effective (Geller et al., 2016; Sheridan & McArdle, 2015). Reward and punishment systems, Sheridan and McArdle (2015) note, ruin engagement and are detrimental to wellbeing. Similarly, Zugai and colleagues (2013) explain that strict universal rules are no more effective in resolving symptoms than a flexible, individualized approach and that patients tend to see strictness as punitive.

Feeling overwhelmed. Several participants recalled feeling totally overwhelmed by hospital treatment and described a sense of being thrown into the deep end with little preparation

or explanation for what was occurring. For many clients, hospitalization is the first time they are faced with the severity of the disorder, which can be anxiety-provoking (Bravender et al., 2017).

Amelia and Kate both described such experiences on their first days in the hospital. Amelia said:

*They ran through a list of a ton of symptoms, both from eating disorder and from general psychological health and that was another, um, uncomfortable and shocking kind of exercise to go through, because it was everything from, “Do you cut yourself? Do you harm yourself? How many calories do you eat a day?” to things like, “Are your extremities cold? Are you losing your hair? Are you purging? Are your teeth falling out?” And it was just this huge overexposure to a whole world I’d never been exposed to, of “Oh my god. Is that what’s in store for me?”*

Similarly, Kate explained, *I just remember, like, um, them, like, making me sign all these contracts and I had no idea what was going on.* While some clients’ first contact with professionals occurs in a hospital setting, for those who start out in outpatient treatment, treatment providers can prepare patients for the possibility of hospitalization from the outset of treatment and this could mitigate part of the shock of hospitalization (Bravender et al., 2017).

Astra described feeling overwhelmed by the expectations placed on her recovery, saying: *when they set these high goals, if you tell any eating disorder person that they have to gain 40 lbs...like, “Excuse me? Screw off”....Maybe set, like, small tangible goals. You know? Like, get to a place where, you know, you’re—and I know it might sound silly to most people but, like, where you’re at least stable.*

The perception that treatment is overwhelming is linked with hopelessness about recovery and treatment dropout (Woodside, Carter, & Blackmore, 2004). Therefore, being clear with patients

about what they can expect from hospitalization is important to minimize this sense of overwhelm and make them more comfortable.

Boredom. Several participants described their time in the hospital as highly boring and uneventful, providing little distraction from the pain and stress of their illness. Several reported it would have been helpful to have more activities available to make them feel more engaged in treatment. Jordana remembered, *I just had to, like, sit there for hours...um, doing nothing.* In a similar vein, Kate stated that, *they take everything from you. So, no computer, no cellphone. You're locked in. Super boring.* Astra remembered telling the staff, *“well, like, I'm just sitting here. You've certified me. There's nothing for me to do,”* and requesting to be allowed to participate in more therapeutic activities. The current participants, like participants in Gueguen and colleagues' (2017) study, were especially bored during times when they had to be on bedrest. While strenuous activities are often necessarily limited to prevent AN patients from over-exercising, some specialized inpatient programs allow patients to gradually incorporate gentle physical activity as they heal, which may help alleviate boredom (Van Ommen et al., 2009; Vandereycken, 2003). This was something Astra suggested could be helpful to provide in general wards where possible, saying:

*that's one thing that [SPECIALIZED INPATIENT PROGRAM] did that was good is they added—once you got to, again, a certain, uh, place—was gentle yoga and I found that really good. Um, again, it's just one thing. It keeps you busy but not overly busy that you're just distracting.*

In their study of youth psychiatric patients, Edwards and colleagues (2015) also draw attention to the issue of boredom and encourage treatment providers to allow patients to engage in activities to make hospitalization more pleasant.

## Abandonment

Participants spoke of feeling abandoned by professionals, either at the end of their hospital stay or while still hospitalized. Related to this was a sense that there was nothing anyone could do to help participants, even though they were still struggling. Feelings of abandonment are a common experience among AN patients (Pemberton & Fox, 2011). Some participants, like Amelia, felt abandoned once staff had completed their duties, for example at the end of meals. She said:

*They did post-meal in the hospital, which is sit with the pain and sit there feeling disgusting and maybe play a board game but...we are going to be watching you like a hawk while you eat and then after that we're going to go sit behind our desks and leave you to your own devices.*

Jordana described feeling abandoned throughout her stay in the hospital, because *that admission they kind of forgot about me....They forgot to, like, check all the stuff. Like, they just kind of forgot to keep giving me heart monitors so that stopped and then they forgot to give me water.*

Other participants described reaching a point in their treatment where they felt all professionals in the hospital had given up on them. Eleni said, *I got to a point where they said, "[O]kay, you know what? We can't, uh, deal with you anymore. We're sending you to the [MENTAL HEALTH INSTITUTION]."* Astra reported a similar sense that there was no one left to help her. She was told she had *used too much now at this point.* Jordana's parallel experience was being told she *wasn't allowed back, um, and that they were not going to see me inpatient or outpatient.*

Multiple experiences participants touched on fell under the category of abandonment. These were Early discharge, Helping oneself, Giving parents too much responsibility and Lack of transition, and “Not my responsibility”.

Early discharge. Many of the participants were discharged either before they had reached the goal weight set by treatment providers or before they felt they had begun to heal psychologically. Brittney’s experience was that, *once you’re done the refeeding...cycle, then they just release you.* A number of participants were discharged, not based on medical criteria but for noncompliance with hospital rules. For example, Kate got *kicked out because I had a symptom...because, you know, can’t be—you have to come in and then all of a sudden be better.* She was told, *“we’re just going to send you home, then, because obviously, you don’t want to be here”.* Nicole said, *they basically kicked me out because I wouldn’t eat a [food item] one time.* Implied in the participants’ description of their releases was a sense that they felt unwanted and believed professionals no longer wanted to deal with them. Pemberton and Fox (2011) identify that being kicked out of a program due to a loss of control over their emotions is a great fear among AN clients. Since Redgrave et al. (2015) found incomplete weight restoration to be a predictor of relapse, it is vital that professionals ensure patients are no longer medically compromised by the time they are discharged.

In other cases, participants were released because their physical symptoms had resolved, though they remained significantly psychologically distressed. Participants lamented that staff recognized only their physical symptoms as legitimate reasons for them to merit help. Kate said, *it’s like, “Well, on paper you’re fine, so we have to kick you out now.”* Similarly, Astra stated, *the minute you start looking better, everybody thinks you’re better.* Rance and colleagues’ (2017) participants also reported being discharged once they appeared physically healthy. However, in

line with what participants in the present study shared, Smith, Chouliara et al. (2016) found that people with AN continue to struggle after they are past the acute phase of their illness.

Helping self. Many participants described instances where they felt they had to take charge of their own recovery. Some participants described this as empowering, where they felt able to make positive changes on their own; others suggested they would have preferred to have had more support from treatment providers. Eleni described a positive experience with taking control of her health, saying:

*I'm in a much better place, all thanks to myself...I'm trying to reach a better life...and it's all due to my own understanding of what I'm going through. I just have to learn how to manage myself properly and not be in a danger zone.*

Astra too reached a place where, *the next year and a half was me kind of keeping myself afloat. I was out of the hospitals and...it actually felt good because I knew that I was able to sustain myself on my own.* Other researchers have described how patients begin to feel empowered once they reach a point in treatment where they can regain control over their eating and that this is a necessary step in recovery (Bezance & Holliday, 2013; Smith, Chouliara et al., 2016). This confidence may have been a factor at play for these young women.

On the other hand, some participants described being unable to get what they needed from the healthcare system and being forced to take matters in their own hands. Amelia stated that, following the end of her formal treatment, she has *been doing, kind of, at-home supportive stuff for the last few years, and started doing things that just made me feel okay. They weren't anything eating disorder [treatment] related.* Kate also turned to a home-based care model with the result that she *was kind of, like, not recovered but, like, maintaining health and everything, um, just still had, like, a lot of [food-related] rules.* While it can have positive impacts on clients'

confidence, no ED client should be left on her own to manage symptoms without support. It is important that these young women not be left to their own devices because the help they need is unavailable.

Giving parents too much responsibility. Several participants who were discharged early said the responsibility for their care had been given to their parents; this often resulted in parents fearing that they were ill-equipped to handle their child's treatment without more extensive support or conflict in the parent-child relationship. Kate stated, *my mom was like, "What?!" Like, "You're gonna send her home with a heart rate of 30?!" and she's like, "What are you talking about?"* Similarly, Nicole recalled her mother's concern, saying *I think my mom was more like, "Well, like, I don't know what I'm going to do if we go home"....They didn't, like, tell her anything...any tips or anything.* Jordana related how her mother was left responsible for taking her back to the hospital if her health deteriorated, saying, *I went home...under the protocol that if, um, my heart rate dropped below 50, my mom would bring me back. If I fasted for a day, I'd be brought back or if I fainted, I'd be brought back.* While parents can be strong sources of support for young women with AN (e.g., Papathomas et al., 2015; Tierney, 2008), it is not appropriate for them to be looking after their children's medical needs.

Some participants reported conflict with parents as a result of their intensive involvement in their care. This was Astra's experience when being unable to access a hospital program forced her mother to assume responsibility for all of her meal support. She recalled:

*We hired a private, um, like, nutritionist, uh, who specializes in [eating disorders]... 'cause I just—I just don't like doing it with my mum....I'm like, "Mom, I want to have a relationship with you down the road and we're not going to get there."*

Bravender et al. (2016) report that many parents of young women with AN see their child's hospitalization as a much-needed time of respite. The current study suggests that at least some parents are not getting this needed relief and that hospitalization causes tension in family relationships.

Lack of transition. All participants said more could have been done to help them with their transition, either back to their regular lives after leaving the hospital or from the child and youth mental health system to the adult one. Participants described feeling lost upon their release, since the amount of structure in the hospital far exceeded that in their everyday lives. Amelia

*remember[s] being discharged and it was, like, this...I had nothing out there. Like, eating disorder treatment is so all-encompassing....It doesn't leave a lot of space for your own life but they expect that you are going to go back to it.*

Other participants reported struggling with differences in the structure of their daily lives compared to that of the hospital. Nicole recalled that she

*had to go back to school and they said, like, snack time was—like, I had to eat my snack right in the middle of my class....They never, like, taught me, like, how to sort of, like, cope, once I got out.*

The issue of adjusting back to regular routines following a hospitalization is a standard experience among youth mental health inpatients and not just those with EDs (Edwards et al., 2015). Nicole was not the only participant to report that no one taught her coping skills in the hospital, such that it was challenging to sustain herself after her release. Eleni suggested it could be helpful to *see what the hospital could provide, um, so [AN patients] could know how to go back home and how to feed themselves.* These participants are not the first to identify a need for more skills training to help patients transition to managing without the hospital's intensive 24–7

care model (Long et al., 2012; Ross & Green, 2011; Smith, Chouliara et al., 2016; Salzmann-Erikson & Dahlén, 2017). Smith, Chouliara and colleagues (2016) present the idea that the hospital environment can be “too safe” and that the absence of triggers in the hospital environment can make relapse more likely. Ross and Green (2011) stress the need to plan patients’ transitions back into the community carefully and Rance and colleagues (2017) suggest follow-up care lasting at least six months.

Several participants talked about being dropped by care providers once they reached the age of majority (18 in Canada). Brittney said:

*My eating disorder clinician just isn't seeing me anymore. There literally is nothing left for them to do....I'm 18 now. I live on my own now. I don't have people watching what I eat....I can't see my pediatrician anymore.*

Nicole explained, after her initial discharge, *I wasn't even allowed to go back in, because...it was, like, two or one week before my 18<sup>th</sup> birthday so they wouldn't admit me again.* Astra described how her transition from youth to adulthood was stressful for her practitioners and how this affected her as a patient. She said:

*At this point, I was 19, so I should not have been on the pediatric ward, but I was...and neither of the two doctors who are the eating disorder doctors, um, wanted to have anything to do with me because I was 19.*

Some participants reported struggling with the lack of preparation for their transition to the adult mental health system. Jordana explained:

*Right now, it's kind of confusing because, um, I just turned 18....I just went to my normal, like, appointment, follow-up, whatever, outpatient, um, in CITY and then they were like,*

*"Okay, well as you know, this is your last appointment with us," and I was like, "What?"*

*Like, three years later and they were like, "Oh, yeah. You don't go here anymore."*

Although a full discussion of the issues patients face when transitioning from youth to adult mental health systems is beyond the scope of the present research, Bove (2011) provides a more in-depth examination of this topic. Her research suggests practitioners treat transition as an ongoing process, educate clients, prepare patients for transition, encourage patients to gradually develop independence, highlight wellness, consider developmental concerns affecting young adults, and solicit patient feedback about the process.

Transition points, both from hospital to community and from youth to adult mental health, are critical points in AN treatment and how they are handled can make the difference between relapse and continued recovery. The combination of the stressful nature of transitions in general with the previously discussed intolerance for uncertainty that is characteristic of AN may partially account for high relapse rates among AN patients discharged from the hospital. Thus, it is crucial that practitioners carefully consider how best to support patients through these challenging periods.

"Not my responsibility". Several participants reported experiences where they felt professionals treated their illness as something that should not be their responsibility or something too complicated for them to address; thus, participants felt there was nowhere for them to go or no one to help them. Kate was told, *"Well, basically you just need to eat, so I can't help you. So, yeah, I'm just going to discharge you."* Astra had a very similar experience, where her doctor kind of sent me home and said... *"Well, yes, she has Anorexia but she just needs to...eat."* In these two cases, participants felt they were expected to deal with the AN on their own. In other cases, participants felt bounced from place to place, with practitioners expecting

other professionals to take responsibility for what they felt was outside of their scope of practice.

Jordana recalled:

*That time, more than ever, like, people were like, “Oh, because she's going to [SPECIALIZED PROGRAM], it's fine, we don't have to deal with her,” so they just left me alone and let me do what I want.... They were like, “[O]Kay, well, whatever, we just have to supervise until [SPECIALIZED PROGRAM] will take you,” so yeah, they got mad at me but they would just kind of ignore me, let me be.*

Some participants also described a sense that professionals felt their illness was too tricky to handle and, thus, their solution was to do nothing and leave patients to their own devices.

Amelia explained that, *nobody wants to talk about the people that don't recover within the first two years and nobody wants to acknowledge that, also, eating disorders continue in many ways.*

Reid and colleagues (2010) found that professionals who treated AN patients in general wards felt pressured to refer them to other services, where they expected their needs to be better met. These professionals believed their lack of experience treating EDs made them ill-equipped to handle their symptoms and felt their team did not have the capacity to provide the level of supervision these patients required. This could be contributing to patients' perceptions that staff do not want to deal with them or see them as a waste a time and space.

AN patients require reassurance that professionals are there to support them throughout their time in the hospital, as well as at the end of their hospitalization. One way of demonstrating this is for staff to build strong, compassionate, and supportive relationships with patients, as I will discuss in the following section.

## Relationships

The small number of studies that address women's experiences with AN indicate that it is largely relational in nature (O'Shaughnessy et al., 2013). AN serves interpersonal functions, such as alleviating worthlessness and defining the self (McNamara & Parsons, 2016). Research indicates that positive and healthy relationships encourage recovery and develop AN patients' self-worth (Granek et al., 2007). Some authors even suggest that training patients in social skills may be a useful intervention (Tierney, 2008). In this study, participants discussed several relational factors, including Isolation, feeling like the Odd one out, Feeling normal, relationships with Other patients, relationships with Friends and family outside the hospital, and relationships with Staff.

Isolation. Many participants reported feeling isolated because there was little contact between them and other people; this included contact with staff and other patients within the hospital, as well as friends and family outside the hospital. Many described hospital rules that limited their interaction with people outside the hospital, such as Kate, who *wasn't allowed to have a cellphone...and no one was allowed to come visit*. Eleni faced similar restrictions and shared the opinion that:

*They should have at least allowed phone calls....I understand Facebook has to be monitored and which websites the child goes on. Whatever. But they could have just put a firewall up, you know? At least let the child engage in some way or another so they don't feel so alone.*

Some participants also described feeling cut off even from other people inside the hospital, such as other patients. Nicole recalled:

*It was weird because, like, we weren't allowed to talk to each other....You couldn't talk to other [ED patients]. Like, unless it was, like, "Hi, how are you?" but even that, they would, like, stop you there, because after, "Hi how are you?" you might talk more to them.*

Astra experienced physical separation from others, when she was *in a separate room again and just by myself all the time and no one was really coming to see me.*

Finally, the illness itself prevented some participants from engaging with others. Jordana explained how damaging this was for her recovery, when she said:

*No one would talk to me in my life. My friends wouldn't talk to me. My family wouldn't. My doctors wouldn't. Um, so I literally just didn't have anyone to talk to. I had nothing to do ever, so there wasn't even motivation to do anything to change....No one was doing anything and I was just isolated.*

Previous research has discussed how people with AN keep others at a distance (Williams et al., 2016). This is partly because AN impacts emotion processing (Kyriacou et al., 2009; Williams et al., 2016) and partly because they feel others do not understand the disorder (McNamara & Parsons, 2016). Because participants experienced isolation as damaging to their recovery, it is paramount that practitioners consider how they might build in more opportunities for patients to connect, not just with outside people in their lives, but also with staff and patients within the hospital setting.

Odd-one-out. Participants frequently described feeling out of place or different in their interactions with other patients or other people in their lives. Many research participants with EDs report having felt isolated and out of place for their entire lives, well before the onset of the ED (O'Shaughnessy et al., 2013). Mira's description of feeling different from others in her family reflected this. She said, *not all of my family looks like [me], so they just see me as weird*

*and unhealthy, no matter what I do.* However, there were also specific features of the hospital environment that made participants feel like outsiders. One was cohabitating with other mental health patients who did not have EDs. Brittney explained:

*It felt kinda weird, 'cause the mental health patients, like, they ate fine...and then I had to have a nurse sit with me for every meal....They were perfectly fine with food, whereas with me it was like this struggle. And I used to—the first couple days for my first two admissions, I would cry every time I had to eat.*

Another ostracizing factor was the ages of other patients, since participants who were close to transitioning to the adult system remained with much younger participants. This happened to Nicole, who said, *there was, like, other people on the ward I was on but they were, like, really young and even if they were my age, I wasn't allowed to talk to them.* Astra too was isolated from other ED patients and said, *I was in my own room, so that was different for me. They were all together...so I felt like there was something wrong with me because I was separated.* Finally, Amelia talked about how the whole hospitalization experience left her feeling separate from her peers. She stated:

*When you have a disorder that lasts as long in your adolescence, you miss out on a lot of regular adolescent things, like socializing and going to school, and you end up in a very different place, where you find yourself feeling like you're not really relating to people your age.*

Hannon and colleagues' (2017) participants also reported a sense of being different; in spite of recognizing the value in connecting with others, they avoided doing so for fear of rejection. Kyriacou et al. (2009) note that feeling like an outsider can contribute to an overall fear of social situations that can further ostracize AN clients. Monitoring how this continues to affect

clients once they are in recovery is important, since Stewart (2004) suggests feeling like an isolated outsider may contribute to ED relapse.

Feeling normal. Several participants described the healing effect of relational experiences that were seemingly small or insignificant but made them feel more “normal” and reminded them of their everyday lives outside the hospital. Jordana recalled how *some of the nurses were really sweet and would spend time with me and just talk to me about random things and try to make me feel [better]*. Edwards and colleagues’ (2015) participants also valued these normalizing conversations with staff. Zugai and colleagues (2013) note that lightening the mood by allowing patients to have fun times is positive and normalizing. Several other participants also had experiences with staff or were permitted to connect to other people or activities in their lives in a way that felt closer to normal. For example, Kate described how *the doctor...would sit down and she would talk to me and really genuinely ask me how I was doing and everything like that, which was amazing*. Mira had a similar relationship with a staff person, who *would just sit there and, like, tell me stories from his childhood and it was just, you know, the way he talked about his life, like, so happy and cheerfully like a normal person*. Research shows that some judicious self-disclosures of this type can be helpful in building trust with AN patients (Ross & Green, 2011; Salzmann-Erikson & Dahlén, 2017).

Conversely, participants experienced parts of the hospital atmosphere as highly abnormal and artificial, which made it difficult to recover. Nicole said:

*Nothing about the setting was normal. You don’t go to a dining table and you don’t open a tray that’s been microwaved. Like, nothing about sitting at that table or being on that ward is normal when you leave the hospital. Like, nothing. You don’t not talk to people at the table, you don’t eat microwaved meals.*

One thing, in particular, that several participants experienced as difficult was eating meals under the supervision of nurses who, as Astra put it, were *just sitting there. They're not eating, um, which is also hard. They're kind of just staring at you....The odd time they might have a banana but they usually didn't eat with you.* Zugai and colleagues (2013) advocate for staff eating with patients and making meals a more social experience.

Approximating everyday life as much as possible in the hospital setting is seen as crucial for treatment success (Bezance & Holliday, 2013). Research consistently shows that AN inpatients want to reconnect with real life, people, and activities (Smith, Chouliara et al., 2016). Bakker et al. (2011) explain that such reconnection can include everything from returning to healthy exercise to interacting with peers and family. Feelings of separation from the outside world thwart development and can foster dependence on practitioners (Bezance & Holliday, 2013). Making the hospital feel like everyday life may be challenging due to the artificial setup participants described; however, the experiences they did characterize as normalizing were often small gestures, requiring minimal effort from staff. Therefore, even in the institutionalized hospital environment, staff may have many opportunities to make patients feel more comfortable.

Other patients. Participants' experiences with other ED patients in the hospital were diverse. Some participants described experiences where they felt supported by and connected to other patients. However, many also described an unhealthy sense of competition or feeling disconnected from other patients. Ambivalence about relationships with other patients has been explored in many other studies (Rance et al., 2017; Smith, Chouliara et al., 2016; Tierney, 2008). Vandereycken (2011) asked participants how they felt about being with other AN patients; 40% disliked it, 33% preferred it, and 27% had mixed feelings. Many of the present participants felt

uncomfortable around other ED patients, such as Mira who said, *I always remember, like, the biggest thing for me was that I hated being around other girls that were going through the same thing as me*, or Astra, who said, *there were 4 Eating Disorder patients. That was...very interesting. It was—I didn't like it*. Even participants who did have good experiences with others with EDs in other settings described uncomfortable interactions with them in the hospital. For example, Jordana stated, *they bunked me with another [eating disorder patient], 'cause we were the only ones who weren't contagious. Yeah, so we still talk. She's, like, one of my friends now, but we never talked there. We were both just, like, angry to be there*.

On the other hand, a number of participants described instances where AN patients in the hospital supported one another. Brittney recalled:

*The nurses were concerned that we would be triggering each other, um, but that wasn't the case. That's never been the case that other girls that I've met in hospital....We're more supportive of each other than, um, than triggering each other*.

Due to the previously discussed sense of being isolated and feeling like the odd person out, connecting with others who experiencing similar struggles was a profound experience for many participants. Jordana said:

*It was good, just 'cause, like, I had been, like, so isolated and alone in that for years, like, from not eating, so that was the first time in, like, years and years that I laughed and talked to anyone, so in that way it was helpful*.

Astra simply stated, *it was just nice to be with people who understood and you didn't feel crazy, you know?* Smith, Chouliara and colleagues (2016) address the powerful impact of being accepted by other clients. Connecting with a community of others who are also committed to

recovery can prevent relapse due to shared identity and resistance to stigma (McNamara & Parsons, 2016).

Even in cases where participants were significantly struggling and felt uncomfortable around other AN patients, they reported a desire to avoid psychologically harming others. Eleni described her relationship with a younger AN patient, saying *she seemed very naïve and I didn't want to start influencing her. I didn't want to start giving her bad vibes. I just...kept my distance.*

While participants spoke of mutual support among the young women in the hospital with AN, most also described an (often unspoken) sense of competition between them. Researchers warn that competition and comparison are detrimental to AN clients' recovery (Edwards et al., 2015; Long et al., 2012). Eleni remembered, *in the back of my mind, I was just thinking she was much thinner than I was and I wanted to be that.* Smith, Chouliara et al. (2016) also found that patients feel jealous of other patients who are thinner. Vandereycken (2011) report that it is common for treatment environments to turn into a competition for who can be the “best Anorexic,” a sentiment echoed by several of the present participants. No participants described overt hostility among AN patients in the hospital; rather, they explained that the way other patients acted or thought about themselves had a detrimental effect on their wellbeing. Mira recalled:

*Someone would come over and just, like, say something so negative and it wouldn't be necessarily towards me. It would be, like, towards themselves, [but] it's like, “well if you're going through that and I'm going through the same thing, I should be thinking in the same way as you.”*

Mira also talked about how *new admissions would always affect me a lot and then I would be doing well and then I would just plummet.* Similarly, Jordana described seeing others

struggling and thinking *because they were doing so bad, it was like, “Well, I’m not doing that, so maybe I should.”* In line with Mira and Jordana’s experiences, other research has shown being around others who are not doing well causes ED patients to feel upset and afraid (Smith, Chouliara et al., 2016; Vandereycken, 2011). Furthermore, like Mira, previous participants with EDs have shared that new arrivals are a stressful experience due to distressing memories, wanting to go back into the ED, and fear of judgment (Tierney, 2008).

McNamara and Parsons (2016) explain that, “the extent to which social identities contribute to resilience or vulnerability depends on the norms and values associated with the specific group membership” (p. 664). In the context of inpatient ED treatment, this means that characteristics of the environment within the hospital may impact how the group affects individuals’ recovery.

A final important point participants raised regarding other patients was that of social contagion, either of new ED symptoms or symptoms of other mental illnesses. Astra’s time in the hospital put her in contact with other ED patients who *showed me bingeing and purging, which I had never really heard about before....The thoughts were kind of then in my head of, “Okay, this is interesting. I wonder if I could do it?”* Vandereycken (2003) also spoke about participants whose symptoms worsened through being exposed to practices they had not imagined on their own. His participants described sharing information about new behaviours they could try and strategies for hiding them from staff. Mira shared experiences of developing other mental health symptoms, saying *when I got in there I just started developing...depression, and anxiety and I have all of those but no Anorexia now....Not to say that mental health is contagious but it’s contagious!* This, too, was mentioned in other research, where patients developed symptoms, such as self-harming, after seeing other patients engaging in these

behaviours (Edwards et al., 2015; Vandereycken, 2003). Importantly, participants in Vandereycken's research and the present study reported disliking this aspect of treatment, feeling distressed at how their symptoms increased through exposure to other patients.

Since reports of relationships with other patients and impacts are so variable, it is important to consider what programs might do to foster an environment that maximizes support among patients and prevents competition as much as possible. The relational diversity also speaks to the previously mentioned importance of individualized care.

Family and friends. Personal relationships with family and friends were also described as mixed, consistent with previous research (e.g., Tierney, 2008). While participants mentioned the healing impact of support from significant others in their lives and especially how helpful it was to have visitors in the hospital, they also described conflictual relationships with friends and family (not always at the same time). In some cases, this friction was described as a result of the ED, while in others, it was cited as a pre-existing factor that hindered their recovery.

In cases where family and friends were a positive influence, they were described as a *lifeline*—a key factor separating participants from complete hopelessness in the hospital. Kate captured this sentiment in her statement:

*The thing that...has kept me alive is, like, people in my life coming and speaking and connecting to life again, connecting to people again. Having that bigger picture, having people come in and, like, speak and, like, you know, just be incredible supports.*

With a few exceptions, most participants stated that hospital rules allowed visitors quite freely and that this was a supportive factor in their recovery. As an example, Astra said, *people just came when they wanted, left when they wanted....I did really like it because...I was able to get out of my head for a little bit, just be with people.* Nicole expressed a similar view, saying

*They would let my mom come anytime....Her and my sister would come visit and spend the whole day with me some days....That was positive.* Since, as Bezance and Holliday (2013) note, separating AN patients from the outside world thwarts development and fosters dependence on treatment providers, it is encouraging to see that most programs support these personal connections. In the few cases where visitation was limited, such as when Eleni *could only see immediate family for one hour a day*, participants felt isolated and described it as a challenge to their recovery. Researchers caution that patients should not be completely cut off from people outside the inpatient setting because resuming normal social activities is key to recovery (Bakker et al., 2011; Edwards et al., 2015).

In other participants' stories, family relationships were a stressor that impacted their recovery. Brittney found it difficult to cope when released from the hospital due to her *family dynamic—my mom yelling, my grandparents stressed, my brother crying all the time because my mom was yelling*. Mira, too found going home difficult, due to her family's beliefs about her illness that formed during her stay in the hospital. She said, *my aunt would call me over and she'd be like, "Hey, I saw you running past my house. I want you to, um, know that you're looking very thin and that you need to, like, watch yourself."* It is not uncommon for hospitalized youth to feel stigmatized by their families, especially following their release (Edwards et al., 2015). Research shows that, to be supportive, friends and family must have some understanding of participants' illness; when they do not, their involvement can be a hindering factor (McNamara & Parsons, 2016; Tierney, 2008).

For some participants, the AN itself was a source of conflict between them and significant people in their lives. Not surprisingly, research shows AN has a tremendous impact on families (Salzmann-Erikson & Dahlén, 2017). Astra described tension in her relationship with her

mother, where *we argue all the time. I don't want this anymore*. Some participants reached a point in their illness where they felt friends and family had given up on them. Jordana said:

*All my friends were frustrated, because I was back and my parents would get mad at me when I wasn't eating and then they were frustrated that I was back after [SPECIALIZED INPATIENT PROGRAM] and the doctors were and the nurses were and so I pretty much had, like, no one.*

Eleni explained that, *yes, I am still struggling and yes, I still have issues, and yes, everybody in my life is kind of like, you know, [LAUGHING] "We're done with you."*

Papathomas and colleagues (2015) found that parents also shared concerns about the effects of AN on their relationship with their ill child. They note that, because AN involves such a high degree of ambivalence, the bond that keeps families together while the child is committed to recovering is often tested during times where motivation wanes. Educating AN patients' family and close friends about the nature of AN might help preserve these relationships at times when the AN becomes stronger, when support is most needed. Having weaker connections when the ED at its worst is a commonly-cited barrier to recovery and anything that can be done to reverse this could support long-term recovery.

Staff. A positive therapeutic relationship with staff is a crucial component of recovery for hospitalized patients (Bryson et al., 2017; Rance et al., 2017). When such a relationship exists, it can promote change towards wellness; for example, clients' early perceptions of the therapeutic alliance predict faster weight restoration (Salzmann-Erikson & Dahlén, 2017). It is even argued that the content of treatment is less important than relationships with staff (Smith, Chouliara et al., 2016). The essential parts of the therapeutic relationship to support patients with AN are:

seeing patients as allies, open honest communication, and trust (Salzmann-Erikson & Dahlén, 2017).

A key concern for all present participants was the amount of compassion they experienced from hospital staff. Many participants described powerfully healing experiences where practitioners treated them with kindness and compassion, while several also described painful experiences where they experienced little to no compassion. Salzmann-Erikson & Dahlén (2017) emphasize the benefits of having emotionally available staff members who prioritize spending time with clients. While this may seem like a difficult thing to do in a busy hospital setting, these authors also found that brief daily supportive interactions can even be better than weekly therapy sessions. Participants in the current study supported this finding, by citing small acts of kindness that likely seemed insignificant to staff but made a tremendous difference to participants. For example, Amelia recalled a practitioner who *just talked about the weather and she did the EKG and she was very gentle*. A few participants recognized a difference between staff on pediatric wards, as compared to general medical wards or psychiatric wards. Brittney's *experience with the pediatric nurses is they're all very sweet and they're all very, like, calm and they're very docile....They're not, like, forcible, even when I got my NG in my last admission in July*.

Kate's suggestion for how staff could form supportive, compassionate relationships with AN patients was *following through, but being, like, compassionate and like kind about it, and, um, and recognizing the struggle. Like, that it is hard and it's not easy and, um, but it is important*. Salzmann-Erikson and Dahlén's (2017) research supports Kate's assertion that when staff impose structure, it must be paired with appropriate concern and empathy for the distress this can cause clients. Supportive relationships are crucial, since they can foster engagement and prevent dropout from treatment (Bezance & Holliday, 2013). The qualities of the positive

relationships described by participants mirror Jordan's (2017) description of *growth fostering relationships*, in that they made participants feel worthier and more positive about connecting with others.

A lack of compassion from some staff members was one of the most emotionally charged topics that came up in the interviews. Multiple participants became tearful when talking about experiences where they felt they had not received any compassion from practitioners in the hospital. Mira recalled, *the nurses would make no...effort to, like, even hide that they were talking shit about us....I thought that was really petty*. On a similar note, Jordana stated, *one of [the staff members] just, like, refused to talk to me and she, like, rolled her eyes when I started crying*. Unfortunately, a lack of connection with practitioners and the feeling that staff do not understand client's experiences are common in inpatient AN treatment (Rance et al., 2017). Several participants, such as Amelia, attributed the lack of compassion they received directly to their diagnosis, stating that:

*If this was something different [not AN],...there would just be kind of a, "We're just kind of going to hold your hand with where you are at now and let us know what you need and we're going to work to let that be a part of your treatment."*

It can be difficult to establish a therapeutic relationship with AN patients because they may strongly identify with their illness, their cognitive functioning may be impaired, and they are often forced into treatment against their will (Salzmann-Erikson & Dahlén, 2017). Salzmann-Erikson and Dahlén (2017) attribute hostility on staff members' part to a reaction to self-loathing in the client, something they believe could be remedied through more extensive staff training. A study by Ramjan & Gill (2012) examined nurses' experiences in a hospital program for AN and found many of them reported having to shut down or *go on autopilot* to cope with the stress of

the job. Having support from colleagues could enable hospital staff to be more compassionate towards their patients and develop trusting relationships with them (Salzmann-Erikson & Dahlén, 2017).

Several participants reported that, over time, they began to lose faith in the treatment providers responsible for their care. This disenchantment was often related to a sense of “shutting down” or suppressing their authentic feelings and desires by going into a sort of survival mode. There were a number of different things practitioners did that caused participants to lose trust in them. One of these was to make negative comments about the participants that the participants later learned about in one way or another. Kate recalls how she *stopped talking because I was like, “Well, they’re all talking behind my back, saying things that aren’t true.” I didn’t trust them. I totally shut down.* Another thing that practitioners did that led participants to distrust them was getting participants to open up and then using what they shared in ways they perceived as harmful or damaging. Amelia explained:

*I was being very vulnerable and opening up with everybody, answering their questions and, dramatically, a few months later, I was being labelled again and again as involuntary, because I totally shut down and I was not answering anything that somebody said. I was walking out of the room. I wasn’t giving anything, because what I was quickly also learning is that anything that I said was being used against me.*

Finally, some participants felt they could not trust practitioners because they spoke or behaved in ways that participants viewed as dishonest. For example, when Astra became very ill but was not admitted to the hospital, she became *angry at HOSPITAL, because I thought, “How come they admitted me every other time?” And all, like, “They shouldn’t have been admitting me. I was too fat back then.”* Eleni described a vague sense of being unable to trust what one

staff member said, saying *I can't explain it but she never quite, uh, leveled with me*. Research shows that distrust on either the staff members' or the client's part can damage the therapeutic relationship (Bakker et al., 2011; Pemberton & Fox, 2011; Ramjan & Gill, 2012). Unfortunately, such distrust appears commonplace in ED treatment (Pemberton & Fox, 2011). Smith, Chouliara et al. (2016) find that a lack of trust for practitioners can lead patients to seek out alternative (and potentially unhealthy) sources of support.

### **Summary of Chapter 5**

In this chapter, I presented my interpretation of the themes inherent in the participants' stories, illustrated with quotes from my interviews with participants. Although the narratives represented distinct and unique experiences for each young woman, certain commonalities were apparent across participants' experiences. These were broadly grouped into Lack of Training, Treatment Experiences, Identity, Individualization, Harsh Treatment, Abandonment, and Relationships. The next chapter will discuss the implications of these results, as well as the limitations of the study.

## Chapter 6—Summary and Implications

This study provides valuable insight into how young women remember and narrate their experiences of hospitalization for AN. The research question was, *What are AN participants' experiences of helpful and not helpful factors in hospitalized care that affect recovery, motivation, and subjective well-being?* Participants' experiences with staff, hospital rules and procedures, and other people involved (e.g., other patients, family) varied considerably. This variability is important, because many of the participants stated that not having their individual situations and differences recognized was itself an unhelpful feature of hospitalization. Without discounting the diversity within the ED experience, it is possible to distinguish several key themes that were common across narratives.

First, since hospitalization in general wards is a fairly common occurrence in AN treatment, staff in these settings need some level of *knowledge and training* concerning EDs. The lack of knowledge these participants reported is consistent with previous research where both patients and staff have lamented the lack of ED training for general hospital practitioners (Bezance & Holliday, 2013; Pemberton & Fox, 2011; Smith et al., 2016). Even in cases where training the entire staff is not feasible, having one or two team members who are knowledgeable about AN could be beneficial. Such individuals could support both patients, who would have a safe person to confide in, and other staff, who would have a resource person to answer questions and provide guidance. Related to the lack of ED specialization is the minimization of *psychological aspects* of AN. In addition to specific ED training, some degree of general mental health knowledge is critical for the successful treatment of AN. It would also be helpful for these patients if at least one mental health practitioner (e.g., counsellor, psychologist, social worker)

was involved in their care. For some participants, this was not the case and hospital professionals dealt only with their physical health.

*Identity* was a critical concern for all of these young women. Many described tension between competing identities. While most had some sense of a preferred or authentic sense of self, they felt forced to adopt a particular identity, either through being treated synonymously with their ED by professionals or being continually told what to do by the ED voice in their head. Reconnecting with different facets of identity unrelated to the ED was cited as central to recovery, something several participants either experienced themselves or heard from other recovered people. Participants saw discovering or rediscovering their sense of self as a crucial step in the healing process.

Whether experienced as positive or negative, *relationships* with other people significantly influenced participants' hospitalization experience—this finding is consistent with the emphasis on relationships espoused in RCT. Instances of supportive and unsupportive relationships with family, friends, staff, and other patients were all described. Participants cited family and friends as a source of significant support and typically saw it as helpful when hospital programs facilitated their involvement. Some family relationships were more fraught; this was often a case of family members lacking knowledge of EDs or support from professionals to be involved in a helpful manner. Family members (particularly parents) were often expected to take on a greater role in participants' treatment than was appropriate; this put intense pressure on them that strained their relationship with the participant. Participants also frequently referenced the importance of relationships with others in the hospital, including staff and other patients. Participants appreciated staff who took the time to get to know them and validated their experiences. On the other hand, when staff dismissed or trivialized their experiences, participants

felt isolated and like there was something wrong with them. Participants' interactions with other patients were mixed at best and counterproductive at worst. Sometimes being around others struggling with similar issues normalized what they were going through and this was a relief. However, there was usually a sense of unspoken competition among patients that worsened participants' symptoms and, through exposure to other patients, participants learned new ED behaviours.

All participants felt their ED narrative was *ongoing* in some way. Although these young women had been out of the hospital for six months to four years, most continued to struggle with AN to some extent. The intensive support provided while hospitalized starkly contrasted with the much less involved treatment participants received in the community and some did not get any support at all following their discharge from the hospital. Participants expressed a wish for more support when they were not acutely ill, because they feared being unable to maintain their physical health and having to return to the hospital.

### **Implications for Research**

Considering the diversity of participants' experiences, the qualitative approach utilized was advantageous, because it captured a more detailed and in-depth "snapshot" of the AN experience. The open-ended narrative method allowed participants complete freedom to construct their narrative in whatever way they chose. They were able to include anything in their story that seemed relevant. The minimal structure of the research interviews worked well for this sample, particularly in light of the lack of control participants described in their treatment experiences. The silencing of these young women's voices is highly problematic and they need a platform to have their stories heard and taken seriously. The methodology in this study sought to provide such a platform and return ownership over the narratives to the participants by limiting

the extent to which the researcher guided the interview process. Some participants expressed appreciation at the end of the interview that the study provided a vehicle for their stories to be heard. More qualitative studies would enable researchers to identify additional contextualized experiences to inform research and practice for this population.

### **Implications for Theory**

The results of this study suggest both SC and RCT have much to offer the study of inpatient AN treatment. Other studies on AN emphasize the roles of identity and relationships in ED recovery and participants in the present study echoed this. Framing the study within the SC paradigm emphasized participant agency. SC is particularly appropriate in a setting where participants feel a particular identity is forced on them and their choices are severely limited. As Gergen (2011) observes, SC allows individuals to continuously construct their own identity through dialogue and interaction with others; the research interviews were one avenue for such self-defining conversations to take place. The SC framework allows participants the space for self-exploration and to assign their own meanings in making sense of their experiences. It is important for building trust with individuals with AN that they not feel powerless. As AN patients often become trapped in struggles for control with people in perceived positions of authority (e.g., doctors, nurses), hearing their authentic perspective depends on the researcher's ability to avoid repeating these problematic dynamics, so the participant has ownership over the process.

Given that (re)building an identity is a central part of these young women's recovery narratives, involvement in this type of research could serve the additional purpose of helping them explore their identity. Reflecting on the meaning of their experiences in the hospital may have helped these women discover certain insights or reframe parts of their experience in a

different light. Although these stories form an integral part of participants' histories, they may not have previously had the experience of relating them in this particular format and, in doing so, it is possible they reflected on aspects of their identity in a new way.

RCT emphasizes the growth women experience through supportive interpersonal relationships (Jordan, 2017). Its emphasis on the deeply painful experience of isolation from others was consistent with participants' description of disconnection, whether it was through physical isolation, such as being separated from other patients, or emotional invalidation when someone misunderstood aspects of their experience. Conversely, many of the descriptions of healing involved normalizing interactions with a supportive other, who could be a staff person, friend, or family member.

The experience of *condemned isolation* as defined by Jordan (2017) stems from being in the less dominant position in a power-over relationship. The participants in this study experienced power-over relationships when being coerced with threats of losing privileges or forced to comply with treatment against their will. The fear of punishment and rejection led these women to disguise their authentic needs and feelings, resulting in disengagement from other people and shame. These dynamics play a role in the maintenance of the ED, since AN thrives in the absence of other trusting relationships. When patients are isolated with nothing but their ED for comfort, there is little motivation to engage in treatment or work towards changing their behaviour. The opposite of power-over relationships and condemned isolation are growth-fostering relationships and connection. These, too, were part of participants' experiences when someone validated and normalized their experiences. That does not mean the individuals who provided these safe relationships were able to understand participants' experiences perfectly, nor that they knew exactly what to say at all times. Consistent with RCT, it was these individuals'

willingness to admit their limitations and continue to be there for patients that made these relationships so profoundly healing (Jordan, 2017). Participants suggested that just voicing their needs and having them heard by professionals would be enough to help them with their recovery.

### **Implications for Practice**

The findings of this study could be harnessed both by individual clinicians and treatment program designers to improve outcomes for young women hospitalized for AN. The participants described aspects of the hospital programs that facilitated or hindered their recovery, as well as staff members' specific attitudes or actions that were helpful or not helpful.

Mental health and specialized support. An important way programs could be improved is by providing support that is specific to ED dynamics, as well as general mental health support. Even a basic level of ED-specific knowledge and training is often unavailable for general hospital staff who are likely to come into contact with AN clients. Training could improve recognition of AN presenting symptoms, increase staff knowledge about what behaviours to look for, and build skills for compassionately confronting clients. Growing staff members' awareness about the etiology of EDs may reduce their susceptibility to the influence of common myths about the nature of AN. Patients want practitioners to understand what they are going through to the extent possible, so that they will not be blamed for their illness and staff will not assume they do not want to get better when they engage in ED behaviours. Additionally, training could alleviate staff discomfort with treating EDs, which might, in turn, improve their capacity to connect with patients. The psychological aspect of EDs is as much a priority as treating physical symptoms, since it is important—often more so than physical treatment—to patients; failure to address this side of AN can leave patients vulnerable to relapse, even once they are physically well. Involving mental health practitioners such as counsellors, psychologists, or social workers

is necessary for a holistic recovery from AN. Individual support from a mental health professional while in the hospital could prevent clients feeling like their priorities are not being addressed and support their long-term recovery. Additionally, having these professionals available to share recommendations and answer questions for staff members who are less familiar with mental health and EDs could alleviate some of the anxiety they feel about treating AN patients.

Building trusting relationships. The crucial role of relationships in these young women's lives is important for both individual practitioners and program designers to keep in mind. Hospital visitation policies should not overlook the sense of hope participants gain from remaining connected to friends and family, particularly in light of rampant feelings of isolation among this population and the resulting psychological damage participants report. Tantillo and colleagues (2013) describe AN as a "disease of disconnection" (p. 23), meaning it is inherently isolating. Therefore, any attempts AN patients make to reconnect with important others should be encouraged. Care providers can also forge their own healing connections with AN clients. Participants' reflections emphasized the positive impact of staff members who took the time to build relationships with them and showed genuine concern for their needs. When staff heard participants' voices, they found this helped their recovery. There are also risks, in that feeling invalidated by staff comments was cited as having an equally powerful negative impact on recovery. The key component in patient–staff relationships was the amount of compassion professionals conveyed. Participants were deeply affected by staff members who treated them with kindness, even if there was little they could do to improve their situation; they were equally

hurt when staff displayed little compassion by dismissing their concerns or blaming them for their symptoms.

Program structure and consistency. Structure and consistency were often highlighted as helpful features of programs, though participants experienced overly strict rules as stifling and oppressive. Participants shared that a lack of predictability and routine caused them significant anxiety. It was important for these young women that all staff be on the same page about what patients are and are not allowed to do. Consistency is essential for promoting a sense of safety for these young women who frequently feel their world is chaotic and unpredictable. Previous research has already identified the need for consistency in program rules (e.g., Zugai et al., 2013); however, a related recommendation that has not appeared in previous research is for consistency in which staff are responsible for participants' care. Participants found it stressful to have many different people involved in their treatment. In a busy general ward with a large team, decreasing the number of professionals involved in a patient's care is likely not practical; however, efforts could be made to make the experience more comfortable for the patient. For example, a nurse might warn patients when their shift is ending and perhaps introduce them to the person relieving them. Many of participants' experiences of being overwhelmed by contact with too many professionals occurred at the beginning of their admission; streamlining intake processes so that clients do not have to re-explain their story to many different practitioners could alleviate some of their stress during this already difficult process. More communication among team members could also relieve clients of the responsibility of answering the same questions for many people. For professionals whose involvement is more intensive (e.g., social

workers, specialist doctors), it might be feasible to assign one person to each patient so patients do not have to repeat themselves.

Ongoing support. All participants described at least one relapse in their narrative, and several spoke of feeling abandoned by treatment providers. Tasake et al. (2017) identify that AN is a long-term illness in the majority of cases and, therefore, planning for long-term support is essential. Having at least one professional consistently involved throughout transition(s) from inpatient care back into the community was cited as helpful by all participants who experienced this. Upon discharge, patients must be connected with appropriate supports in the community, preferably a multidisciplinary team monitoring all aspects of their health as they make the difficult transition back to everyday life. The other type of transition that needs to be bridged is between the youth and adult mental health systems. Participants described a lack of preparation for their movement between these systems, sometimes resulting in not receiving services once they were legally considered adults. Plans need to be put in place for this transition so these young women continue to receive support until their ED is resolved. Previous research by Bove (2011) called for changes in the management of young women with EDs' transition to the adult mental health system; it seems patients continue to lack support through this transition and changes are still needed.

Fostering identity. The centrality of identity in these young women's narratives cannot be overstated. Identity is thought to be implicated in the onset of AN as well as recovery from it (e.g., Bravender et al., 2017; McNamara & Parsons, 2016; Williams et al., 2016). Importantly, for the development of a distinct identity, staff must recognize the uniqueness of individual AN clients; treating clients as though they are simply the product of their disorder was reported to be unhelpful and prevent healing. Participants in the present study noted that finding their voice and

developing a non-disordered identity were critical in their recovery process. Clinicians could actively encourage this by engaging patients in activities aimed at fostering their sense of identity. These activities could also help to alleviate the boredom some participants felt during their time in the hospital. Identity growth could also occur more organically through conversations between staff and clients, provided there is enough safety in the relationship for clients to feel comfortable broaching this topic.

### **Limitations**

As with any research project, the current study has limitations that must be noted. The aim of qualitative research is not to generalize findings broadly to an entire population. Still, it bears mentioning that one cannot assume the results of this study apply to all young women with AN. The research was conducted in a specific context at a particular time; there are likely similarities of experience among other young women hospitalized for AN, but it is not possible to draw conclusions about anyone outside of this context. Additionally, while AN is most prevalent in young women, it occurs in people of other ages and genders as well—their experiences may be different from those of the present participants. Furthermore, the analysis was based on my subjective interpretation of the data. Other researchers may have different interpretations.

The stories shared by these young women were reconstructions based on their recollections of their time in the hospital. To provide sufficient distance from and opportunity for reflection on the experience of being hospitalized, participants were required to have been out of the hospital at least six months. In some cases, the time since their release from the hospital was significantly longer. It is possible specific details were misremembered or forgotten entirely. No research interview can ever wholly capture the nature of someone's experience. The goal of these

interviews was not to obtain a perfectly accurate representation of participants' hospitalization, but to illustrate broad commonalities in the hospitalization experience.

### **Concluding Thoughts**

To conclude, I would like to recognize the valuable contribution these young women made to our understanding of AN by sharing their stories of being in the hospital. The narratives shed light on the complexity of this disorder that cannot be overlooked in the design of successful inpatient programs. The participants expressed a wish to be meaningfully involved in their own care and called for staff, program designers, and researchers to include patients in planning ED services. By establishing trusting and mutually respectful relationships with AN patients, treatment providers can increase their quality of care and help promote the construction of an identity free from AN that can sustain these women through their recovery.

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# RESEARCH PARTICIPANTS NEEDED

- ✓ Have you been hospitalized for Anorexia Nervosa in a general psychiatric or pediatric ward?
- ✓ Have you been out of the hospital at least 6 months?
- ✓ Are you between 17 and 25 years old?

**I want to hear from you!**

I'd like to  
hear **YOUR**  
story!

I am a Counselling student at the University of Victoria and collecting young women's stories about being hospitalized for Anorexia for my Masters thesis.

If you or anyone you know has a story to share for this research, please email [jcumming@uvic.ca](mailto:jcumming@uvic.ca) or call/text 778-678-1620.

Thank you! ☺  
Jessica Cumming



**University  
of Victoria**



Social Sciences and Humanities  
Research Council of Canada

Conseil de recherches en  
sciences humaines du Canada

**Canada**<sup>5</sup>

**Appendix B— Recruitment Form**

**Jessica Cumming**  
**University of Victoria**  
**Department of Educational Psychology and**  
**Leadership Studies**

*Key Informant Recruitment Form*

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**Young Women’s Experiences of Hospitalization for Anorexia Nervosa**

Hello!

My name is Jessica Cumming ([jcumming@uvic.ca](mailto:jcumming@uvic.ca)), and I am a Master’s student in Counselling Psychology at the University of Victoria (UVic). I work in an outpatient clinic in Greater Vancouver with young people who are being treated for eating disorders and, for my thesis research, I am collecting the stories of young women who have been hospitalized in general psychiatric or pediatric wards for Anorexia. This letter is to invite you to share your story as part of my study. My project is co-supervised by Dr. Anne Marshall ([amarshal@uvic.ca](mailto:amarshal@uvic.ca)) and Dr. Natalee Popadiuk ([popadiuk@uvic.ca](mailto:popadiuk@uvic.ca)) in the Educational Psychology and Leadership Studies department at UVic. If you have any questions or concerns about the project, please feel free to contact me or my supervisors. This research is being funded in part by the Social Sciences and Humanities Research Council of Canada.

A common theme I hear from the young people I work with is that their voices are not always heard when they ask for what they need in their treatment. Research that has been done on eating disorders also shows that clients’ experiences are not always considered or understood. **The purpose of my study is to explore the hospitalization experience, particularly looking at what young women consider helpful or not helpful in their journey towards recovery.** The research question is: “what are AN participants’ experiences of helpful and not helpful factors in hospitalized care that affect recovery motivation and subjective well-being?” I hope that your stories and experiences will help improve hospitalization experiences for young women with Anorexia in the future.

I am inviting you to share your story for this research because you are a young woman between the ages of 17 and 25 who has been hospitalized for Anorexia and you have been out of the hospital at least six months. Your individual interview will take between 60 and 90 minutes at an agreed-upon location in the Lower Mainland area. If you heard about this study from your counsellor, he/she will know that you have been invited to participate but not whether you have actually participated—the counsellors who are helping me recruit for the study are not involved in the research. I will not be telling counsellors who decides to participate. Whatever you decide will not affect your relationship with your counsellor or the agency where they work.

If you would like to participate please email me at [jcumming@uvic.ca](mailto:jcumming@uvic.ca) or call/text me at (778)678-1620 to set up an interview.

Participating in the study should not involve any inconvenience for you other than the time to participate in the interview, and possibly to travel to the interview.

The potential benefits of your participation in this research include contributing to knowledge and understanding about helpful practices in inpatient care for Anorexia.

It is possible that talking about your experiences in the hospital may bring up uncomfortable feelings. If this happens, please tell me—you are welcome to pause or stop the interview at any time. If you have a counsellor, you will be encouraged to discuss your reactions to the interview with him or her. If you are not currently seeing a counsellor, I can refer you to one. The potential benefits of your participation in this research include contributing to knowledge and understanding about helpful practices in inpatient care for Anorexia Nervosa.

If you have any questions or concerns about this study, you are welcome to let me or my supervisors know. You can also ask anything about the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Board at the University of Victoria, 250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca).

Thank you.

Jessica Cumming  
[jcumming@uvic.ca](mailto:jcumming@uvic.ca)  
(778) 678-1620

**Appendix C—Consent Form**

**Jessica Cumming**  
**University of Victoria**  
**Department of Educational Psychology and**  
**Leadership Studies**

*Key Informant Consent Form*

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**Young Women’s Experiences of Hospitalization for Anorexia Nervosa**

Hello!

My name is Jessica Cumming ([jcumming@uvic.ca](mailto:jcumming@uvic.ca)), and I am a Master’s student in Counselling Psychology at the University of Victoria. I work in an outpatient clinic in Greater Vancouver with young people who are being treated for eating disorders and, for my thesis research, I am collecting the stories of young women who have been hospitalized in general psychiatric or pediatric wards for Anorexia. My project is co-supervised by Dr. Anne Marshall ([amarshal@uvic.ca](mailto:amarshal@uvic.ca)) and Dr. Natalee Popadiuk ([popadiuk@uvic.ca](mailto:popadiuk@uvic.ca)) in the Educational Psychology and Leadership Studies department at UVic. If you have any questions or concerns about the project, you are welcome to contact me or my supervisors at any time. This research is funded in part by the Social Sciences and Humanities Research Council of Canada.

**Purpose and Objectives**

- The purpose of my study is to explore the hospitalization experience from the patient perspective, particularly looking at what young women consider helpful or harmful in their journey towards recovery.

**Importance of this Research**

- A common theme I hear from the young people I work with is that their voices are not always heard when they ask for what they need in their treatment
- Research on eating disorders also shows that clients’ experiences are not always considered or understood
- I hope that your stories and experiences will help improve hospitalization experiences for young women with Anorexia in the future

**Participant Selection**

- I am inviting you to share your story for this research because you are a young woman between 17 and 25 years old, you have been hospitalized for Anorexia, have been out of the hospital for at least six months and have expressed interest in sharing your story

**What is Involved**

- If you agree to be interviewed, you will:
  - Meet with a me for 60—90 minutes to share your hospitalization story somewhere in the Greater Vancouver area (or via Skype)
  - Be tape-recorded. I will listen to the tapes and transcribe your story word for word

- Give me permission to use your answers to our questions as part of my thesis. Your name will not be shared with your answers.

### **Risks**

- It is possible that talking about your experiences in the hospital may bring up uncomfortable feelings.
- If this happens, you are welcome to pause or stop the interview.
- If you have a counsellor, you are encouraged to discuss any discomfort with the interview with him or her. If you are not currently seeing a counsellor but would like to debrief your interview with one, I can give you names of counsellors you could see.

### **Potential Benefits**

- The potential benefits of your participation in this research include contributing to knowledge and understanding about helpful practices in inpatient care for Anorexia.

### **Voluntary Participation and Relationship with Participants**

- Your participation in this research must be completely voluntary
- If you decide to be part of the study, you can change your mind at any time without explanation or consequences
- You can choose not to answer certain interview questions without explanation or consequences.
- If you decide to drop out of the study at any time after you have shared part or all of your story, I will ask you if you want what you have already shared to be part of the research. If you say no, I will destroy your tape and any transcripts from your interview
- If you heard about this study from your counsellor, he or she will know that you have been invited to participate but not whether you have actually participated—the counsellors who are helping me recruit for the study are not involved in the research. I will not be telling counsellors who decides to participate. Whatever you decide will not affect your relationship with your counsellor or the agency where they work.

### **Anonymity**

- I will not use your name in any published results from this research. You will get to choose a code name that will be used instead of your name in my thesis.
- I will ask you not to share your name, anyone else's name, or any other information that could be used to identify someone. If you forget and accidentally mention someone's name, I will change it or leave it out when I write the transcript of the interview.

### **Confidentiality**

- This form and the transcript from your interview will be kept in a locked drawer.
- Electronic transcripts will be stored in password protected computer files.
- I will have to tell someone if you tell me that you are intending to harm yourself, harm someone else, or if you tell me that you or someone else who is under the age of 18 is being abused or neglected.

**Dissemination of Results**

- The results of my study will be published in my Master's thesis, which will be available to read on the UVic website
- A summary of my study results may be published on the Social Sciences and Humanities Research Council website
- I will share a summary of my study results with counsellors and other professionals who are interested in using these results to inform the treatment of young people with Anorexia

**Disposal of Data**

- I will delete electronic copies of the tapes and transcripts and shred any paper copies after 5 years

**Contacts**

- You can check the ethical approval for this study or share any concerns by calling or emailing the Human Research Ethics Office at the University of Victoria (250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca)).

*Please ask any questions about the study at any time! 😊*

Your signature below indicates that you understand everything listed above about participating in this study and that I have given you an opportunity to ask any questions you might have.

Name of Participant (print)

Signature

Date

**Appendix D—Interview Script**

**Jessica Cumming**  
**University of Victoria**  
**Department of Educational Psychology and**  
**Leadership Studies**

*Key Informant Interview Script*

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**Participants' Qualitative Experiences of Tertiary Care for Anorexia Nervosa**

Thank you for participating this research project. For the sake of confidentiality, I will ask you to please not refer to other people by name. I'd like to hear your story of being hospitalized. I'm particularly interested in the things that you thought either helped or got in the way of your recovery and some of the things that hospital staff specifically did to help or hinder your recovery? What practices would you like to see changed in hospital programs for youth with Anorexia Nervosa? What would you like to share with the people that design hospital programs for Anorexia Nervosa?

I'm just going to take a moment to see if we've covered everything. Perhaps you can take a moment, too, to think about anything else you'd like to tell me about ...

You are always welcome to get in touch with me if you think of anything else you would like to add. Would it be ok if I contact you later if there's anything I need to clarify?

(Open questions such as, "Can you tell me more?" or "Can you give me an example?" will be used to facilitate the interview process)