

FROM TREATMENT TO RECOVERY: FAMILY, HEALTH, AND SOCIOCULTURAL  
IMPLICATIONS OF ANOREXIA NERVOSA

By

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Anorexia nervosa (AN) is a life-threatening biopsychosocial-spiritual illness that crosses all social locations (i.e., ages, gender identities, sexual orientation, races, ethnicities, socioeconomic status, and body sizes), negatively impacting couple/family systems. While family-based treatments have a well-established evidence base in treating AN, it is unknown how relationally-oriented treatments (i.e., couple and family-based) address the whole person with AN (i.e., biopsychosocial-spiritual) from a dyadic/family systems lens. Recovery is a process fraught with obstacles such as persistent mental health challenges and societal ideals/standards. Sociocultural risk factors such as diet culture (i.e., a system that elevates physical health and perpetuates myths and lies about food choices, eating behaviors, and body types) is an understudied phenomenon which may also complicate recovery. Since risk of relapse is highest following treatment, it is important to understand the biopsychosocial-spiritual health experiences of diet culture for individuals in recovery from AN. The purpose of this dissertation is to address gaps in relationally-oriented treatment and recovery research. This dissertation contains six chapters, including: (1) an introduction chapter to the history of AN diagnosis, treatments, and social location factors, (2) a literature review of biopsychosocial-spiritual health risks and symptoms associated with AN, (3) a systematic review of relationally-oriented

treatment studies for AN and how they are addressing biopsychosocial-spiritual health and social location from a dyadic/family systems perspective, (4) a methodological chapter describing the mixed methods approach to the original qualitative study, (5) an original research study demonstrating the lived experience of diet culture for individuals in recovery from AN, and (6) a discussion chapter that pulls together the major findings to provide clinical resources for healthcare providers.



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by

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## DEDICATION

This dissertation is dedicated to my family and the countless others who share the burden of a life-threatening illness with their loved ones yet do not waver in their support or loving care. To the families who persevere and continue to selflessly sacrifice for the sake of your loved one's life—the unsung heroes—you inspire me and instill hope for others. To the future families who may be harmed by this illness, act fast, listen to your loved ones, and believe the best—*together*, you will not lose this battle. To my sisters who relentlessly fight for full recovery, you are my *why*.

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To my parents, Joe and Pat, I will always be grateful for your endless support of me and my dreams. Your encouragement, willingness to be a sounding board, and interest in my studies helped carry me through difficult moments. Your generosity knows no bounds. Thank you, Mom and Dad, for teaching me that I am capable. Thank you for your love and steadfastness.

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To my daughters, thank you for your patience, understanding, and love. You have watched me go from being a stay-at-home mom to working full-time to becoming a full-time student. You are resilient in the midst of many changes and I am so proud of how you have adapted to new situations. Thank you for reminding me to live in the moment and be present.

To the participants, thank you for sharing some of the most painful parts of your lives with me. You allowed me to see your vulnerability, and for that, I am incredibly honored. Thank you for sharing your stories with me as you march onward in recovery. You are nothing less than warriors.

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## PREFACE

When I reflect on the trajectory of my life, I am grateful for the inevitable heartaches and joys that have defined me and my sense of purpose. I come from a very loving and stable home environment, the middle child of two happily married parents. I acknowledge I grew up privileged in many ways—White, middle class, able-bodied. I also grew up in a family with mixed ethnicities and attribute my deep appreciation of diverse cultures, ethnicities, and languages to my culturally rich upbringing. I am proud of my family heritage and grateful for how I was raised. I also grew up in a family acquainted with mental health conditions. I experienced firsthand what it is like to be a sibling of sisters battling eating disorders, specifically bulimia nervosa and anorexia nervosa, and the adverse biopsychosocial-spiritual health impact of these illnesses within my family system. In addition to the personal and professional experiences with treatment, I have walked with my sisters through recovery, keenly aware of the persistent mental health challenges following treatment.

Less than a decade before my eldest sister was born, Minuchin and colleagues (1975) published an article on treating anorexia nervosa within the family system. In the late 80s and early 90s—during the development of my elder sister’s eating disorder—family-based treatment (i.e., Maudsley model) was gaining empirical support. Given the time it takes for research to translate into clinical practice (i.e., 17 years; Morris et al., 2011), family therapy had not yet gained the credibility as a recommended treatment by behavioral health providers. Not only were there no published treatment guidelines for my parents, a mental health culture of blaming and shaming families, particularly mothers, for their child’s mental illness was prevalent in psychotherapeutic literature (Neill, 1990). The healthcare system was fragmented and my sister’s treatment was piecemealed with outpatient providers and online support groups. Unfortunately,

as a sibling, I was not integrated into her treatment despite her illness deeply impacting me. It was about a decade later that my younger sister began to struggle with an eating disorder and my professional journey treating eating disorders began.

My younger sister was diagnosed with anorexia nervosa during college. Although this was two decades after family-based treatment was empirically established, there were no recommended treatment guidelines for family-based treatments for young adults with anorexia nervosa. Though her outpatient treatment team was multidisciplinary, providers were not co-located and care was not integrated. It was not until she was in a relapsing phase at the most severe level (i.e., refeeding syndrome) when I became integrated into her treatment team. Since the Maudsley model of family-based treatment for anorexia nervosa was well-established (Lock & Le Grange, 2013), we followed this approach. Looking back, I would attribute her recovery during this critical phase of her treatment to the communion of her treatment team (i.e., dietitian, therapist, medical provider) with her family and the team's ability to support her agency throughout the treatment process. Most importantly, my sister needed to believe that recovery *was* possible and that she was willing to fight daily for her health. While treatment helped stabilize her and restore her physical health, her recovery was possible because other aspects of her health (e.g., relational, spiritual) were elevated, independent of weight and food/eating.

This dissertation is a tribute to my family's experience and my professional aspirations to contribute to the intervention and prevention of anorexia nervosa. My lived experience propels me to provide patient and family-centered care, not disease-centered (Peek, 2009). Families of all social location backgrounds deserve access to family-centered treatment and research. The pain and loss associated with a devastating illness like anorexia nervosa can be healed and restored, and quality of life is possible for those who persevere in their life-long pursuit of recovery.

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## CHAPTER 1: INTRODUCTION TO ANOREXIA NERVOSA: HISTORY OF DIAGNOSIS, TREATMENTS, AND SOCIAL LOCATION FACTORS

Eating disorders (e.g., anorexia nervosa [AN], bulimia nervosa, binge eating disorder) are among the deadliest mental health illnesses (National Institute of Mental Health [NIMH], 2017). Eating disorders are indiscriminate—crossing all social locations (i.e., ages, gender identities, sexual orientation, races, ethnicities, socioeconomic status, and body sizes; NIMH, 2017). Approximately, 28.8 million people alive in the United States in 2018-19 will have an eating disorder at some point during their life (Deloitte Access Economics, 2020). Over the past decade prevalence of eating disorders on a global scale has been steadily increasing according to a recent international systematic review (Galmiche et al., 2019). While the less restrictive criteria used to classify AN (American Psychiatric Association [APA], 2013) has been directly related to its proportional increase—from 8% to 29% of all eating disorders (Fairburn & Cooper, 2011), it is the most life threatening of all eating disorders. AN has a mortality rate six times higher than healthy peers (Fichter & Quadflieg, 2016), and one of the highest suicide risk rates of all mental health disorders, second only to opioid addiction (Chesney et al., 2014).

AN—the focus of this dissertation—is a biopsychosocial-spiritual (BPSS) illness defined by restriction of energy intake relative to requirements leading to significantly low body weight, intense fear of gaining weight or becoming ‘fat’, and body weight or shape disturbance (APA, 2013). Even though weight restoration is critical for reversing the effects of AN, individuals with AN have reported that treatment overemphasizes physical health (Rance et al., 2017) and others have argued that symptom management is not enough for relapse prevention (Kenny et al., 2020). Risk of relapse is especially high within the first year following treatment (Khalsa et al., 2017) and recent evidence suggests that a minority of patients with AN may fully recover

(Franko et al., 2018). Complicating the life-threatening and relapsing nature of AN is the evidence that mental health struggles often precede a diagnosis of AN and persist following treatment (Kaye et al., 2008). As a BPSS illness, there are significant biopsychosocial (Culbert et al., 2015) and spiritual health impacts (i.e., beliefs and values in relation to self, food, eating, and body; Stockford et al., 2019). Therefore, it is important that treatment and relapse prevention strategies for AN are BPSS-oriented. Finally, sociocultural eating disorder risk factors, which have become more relevant and pervasive (e.g., diet culture, social media; Morris, 2020; Sidani et al., 2016) are understudied experiences for individuals in recovery from AN. Given this evidence, it is incumbent upon researchers to gain a better understanding of treatment outcomes and recovery experiences for individuals and family members. Closing these gaps can help improve treatment approaches and relapse prevention.

As a systemic and diagnostically evolving illness, this dissertation project aims to address gaps in relationally-oriented treatment studies and recovery research. The purpose of this chapter is to introduce the theoretical orientation grounding the dissertation project, describe the history of AN as a diagnosis and treatment, and address relevant social location implications. The following chapters will provide a literature review of the main variables under study (Chapter 2), a systematic review (Chapter 3), independent research project (Chapters 4 and 5), and implications/future directions (Chapter 6).

### **Theoretical Orientation of the Dissertation Project**

This dissertation is theoretically grounded in health theories that inform the conceptualization and treatment of and recovery from AN. The biopsychosocial model (Engel, 1977, 1980)—grounded in general systems theory (von Bertalanffy, 1968)—takes into account how multiple systems (i.e., community, family, two-person, person, nervous system, organ

system, tissue, cell, and molecule) interact to influence health. Wright and colleagues (1996) contended for spirituality (i.e., belief systems) to be included in healthcare settings to help families cope with disability and/or illness. Over time, this became known as the biopsychosocial-spiritual (BPSS) framework (Engel, 1977, 1980; Wright et al., 1996). This framework is used to highlight the systemic effect of AN on health, including the couple/family system. AN was originally treated by family therapists grounded in family systems theory (FST; Dare & Eisler, 1997; Minuchin et al., 1978; Selvini-Palazzoli, 1974; Wynne, 1980), which is also based in general systems theory (von Bertalanffy, 1968). FST is grounded in the belief that families are organized wholes with interdependent subsystems (Minuchin, 1985) and must be understood in context of larger systemic influences (e.g., culture, socioeconomic, religion, extended family; Hecker et al., 2003). As such, an individual with AN must be understood and treated in context of the couple/family system.

Social cognitive theory describes how larger systemic influences (e.g., cultural beliefs and values) may influence health beliefs and behaviors by the reciprocal interplay of personal (e.g., self-efficacy, knowledge, outcome expectations), sociocultural (e.g., cultural beliefs/norms), and environmental (e.g., social support, observational learning) factors (Bandura, 1986, 1999). Social cognitive theory also supports beliefs of personal efficacy as foundational to behavioral health change. Personal efficacy beliefs regulate motivation, affect, and cognitive functioning; ultimately allowing individuals to shape the course of one's life. This theory helps to conceptualize the systemic context in which individuals in recovery from AN experience cultural beliefs and values in their environment and the cognitive process by which personal efficacy and knowledge contribute to health-promoting choices (Bandura et al., 1977). Taken together, the BPSS framework, FST, and social cognitive theory provide a robust theoretical

framework for understanding AN—its diagnostic origins, history of family and couple-based treatments, and social location implications.

### **History of Anorexia Nervosa and Treatment**

The nature of AN has conceptually and diagnostically evolved with origins dating back to the Middle Ages (Dell’Osso et al., 2016). While fasting was a common ritual observed among Western European Christians during the Middle Ages as a pursuit for spiritual holiness, historical evidence has revealed accounts of extreme forms of fasting or self-starvation (e.g., “holy anorexia”; Bell, 1987). Prior to any formal diagnosis, these behaviors or rituals had mostly religious/spiritual undertones absent medical or psychopathologic factors (Dell’Osso et al., 2016). It was not until the 19<sup>th</sup> century that AN was medically coined (Vandereycken & Van Deth, 1989). As scientific discoveries advanced, the cause of AN expanded to include multiple contributing factors (e.g., biological and sociocultural; Russell & Treasure, 1989). Decades later, these discoveries and others led to a multifactorial model based not only on the totality of, but interacting biological, psychological, and social risk factors (see Culbert et al., 2015; Levine & Smolak, 2014 for full reviews). Given the multifactorial nature of AN, first line of defense treatments for adolescent and adult AN are systemically and relationally-oriented (e.g., family-based treatments [FBTs]; National Institute for Health and Care Excellence, 2020). In fact, treatment for AN originated with FBTs, which were established over 30 years ago (Dare, 1985; Minuchin et al., 1975, 1978). The following section is a brief historical overview of family systems approaches and current FBT practices.

Minuchin (1975) and colleagues’ (1978) created the psychosomatic family model which described family organization patterns (e.g., enmeshment, rigidity, overprotectiveness, and lack of conflict resolution) and physiological vulnerability in children as the basis for psychosomatic

symptoms in children. The psychosomatic family model became the conceptual framework for FBT for AN, which focused interventions at the family level to change family patterns that were maintaining symptomatic behaviors. Kog and colleagues (1985) later questioned the rigidity of his conceptualization and suggested a continuum of family interaction patterns (e.g., intensity of intrafamilial boundaries, family adaptability, degree of avoidance/recognition of intra-familial tension, and family's way of handling conflicts). They validated Minuchin's theory and likewise found that boundaries, adaptability, and conflict were important family characteristics associated with AN.

### ***Family-based Treatments***

Grounded in a family systems approach, FBTs for AN have ranged from systemic (Shugar & Krueger, 1995), structural (Perlman & Bender, 1975), behavioral (Ball & Mitchell, 2004), and more recently, caregiver-based interventions (e.g., Lafrance Robinson et al., 2016; Rhodes et al., 2009). The most prominent form of FBT for AN is the Maudsley model (i.e., Maudsley-FBT; Lock & Le Grange, 2013), which continues to rank as the most effective treatment for adolescent AN (Lock, 2019). The founders of Maudsley-FBT saw the value and benefit of parent involvement in outpatient treatment and viewed their participation as a resource rather than a hindrance (Le Grange, 2005).

A major tenet of Maudsley-FBT is to empower parents to take charge of their child's weight restoration and healthy eating (Lock & Le Grange, 2013). A major premise of this approach is that the eating disorder has taken control of the adolescent and the parents need to regain control of their child's physical health. Once weight is restored and stabilized, then the adolescent can take control of eating and exercise under parental supervision. Other key tenets include improving the parent-child relationship and helping the adolescent resume normal or

typical development. Although adolescent and family conflicts/issues are deferred until eating disorder behaviors are under control (e.g., food/meal restriction and over-exercising; Lock & Le Grange, 2013), including the family in treatment facilitates positive treatment outcomes.

However, like any treatment approach, there are limitations to Maudsley-FBT.

Maudsley-FBT is a manualized and behavior-focused approach that is not well-established at higher levels of care. The focus on physical health in Maudsley-FBT has inadvertently minimized other domains of health within families (e.g., emotional and interpersonal dynamics). One study, for example, found that parent-focused treatment helped to decrease maternal criticism whereas Maudsley-FBT did not (Allan et al., 2018). Previous researchers have addressed these limitations by testing the efficacy of Maudsley-FBT at higher levels of care (e.g., Halvorsen et al., 2018; Halvorsen & Rø, 2019; Spettigue et al., 2019) and have developed augmented interventions to increase caregiver skills (Hibbs et al., 2015; Peterson et al., 2016) and parent-child dynamics (Wagner et al., 2016). This shift has given way to more family-centered and collaborative approaches to care (e.g., parent-nurse partnerships; Silber et al., 2011) and has inspired treatment approaches to focus on improving both caregiver and patient well-being (e.g., New Maudsley collaborative care approach; Treasure et al., 2015). These approaches aim to increase parent efficacy and remove emotion blocks (e.g., shame, anger, guilt; Lafrance Robinson et al., 2016) in order to facilitate positive treatment outcomes. Findings are promising, suggesting that shifting treatment to focus on parents or caregivers' self-efficacy and interpersonal or relational dynamics reduces maintaining factors associated with AN (Wagner et al., 2016) as well as anxiety and caregiver burden (Merwin et al., 2013). Research evidence has demonstrated that not only do FBTs improve family functioning (Ciao et al., 2015), they also have a stronger evidence base over individual therapies for adolescent AN (Bodell &

Keel, 2010) and superior long-term outcomes compared to individual therapies (Couturier et al., 2013). FBT approaches are also proving efficacious for older adolescents and young adults (Pisetsky et al., 2016). Though not as robust as FBTs, empirical support for couple-based treatments are increasing.

### ***Couple-based Treatments***

Couple dynamics in the context of AN have been studied for over 30 years (Dally, 1984; Van den Broucke & Vandereycken, 1988), yet the development of couple-based treatments lag behind FBTs. Researchers have found that romantic partners have a positive effect on reducing AN symptomatology and other psychopathology (Wierenga et al., 2018) and can play a critical role in recovery (Linville et al., 2012). While there are positive implications for integrating romantic partners into treatment (Kirby et al., 2015; Watson & Bulik, 2013), couple-based treatments were not empirically established until recently (Bulik et al., 2012). Despite the limited evidence, these studies have ranged from strategic couples therapy (Murray, 2014), Maudsley Model of AN Treatment for Adults and Specialist Supportive Clinical Management (Schmidt et al., 2015) to cognitive-behavioral couples therapy and individual cognitive-behavioral therapy (i.e., *Uniting Couples in the Treatment of AN*; Baucom et al., 2017; Kirby et al., 2015)). These approaches have shown to be effective in reducing anxiety and depression, improving relational adjustment (Baucom et al., 2017), increasing body mass index, reducing eating disorder symptomatology, distress, and clinical impairment (Schmidt et al., 2015). Although not without limitations, couple and family-based treatment approaches are beneficial in addressing the BPSS health impact of AN from a dyadic/family systems perspective. Despite the systemic benefit of these treatment approaches, this dissertation will highlight the gap that exists in relationally-oriented treatments in addressing BPSS health from a dyadic/family systems lens. Despite the

rising global prevalence of eating disorders, including AN (Galmiche et al., 2019), very few FBT studies address social location as it relates to AN and non-AN family member (later discussed in Chapter 3).

### **Social Location**

Despite treatment rates skewing toward females (Raevuori et al., 2014), AN or risk of AN does not only affect certain demographics or social locations. Although previous researchers have demonstrated that lifetime AN is higher among White women than non-Hispanic Black and Hispanic women (Udo & Grilo, 2018), likelihood of ever seeking treatment for an eating disorder is significantly lower for racial/ethnic minoritized groups (Coffino et al., 2019). Complicating this finding is the evidence of clinician bias as it relates to race and gender and eating disorder diagnoses (Garb, 2021). Yet, disordered eating or risk of eating disorders is prevalent in diverse social locations (e.g., males [Weltzin et al., 2012], transgender youth [Diemer et al., 2015], Asian female adolescents [Rodgers et al., 2017]). Collectively, these findings suggest that the individuals and families experiencing AN in the general U.S. population is disproportionate to the individuals and families historically represented in treatment studies.

Previous researchers have also found that disordered eating/eating disorder risk factors differ among racial/ethnic groups (Rodgers et al., 2018; Shuttlesworth & Zotter, 2011). For example, low ethnic identity for African American women was associated as a risk factor for eating pathology (binge eating and bulimia tendencies) whereas high ethnic identity was a risk factor for White non-Hispanic women (Shuttlesworth & Zotter, 2011). In a more recent review of eating disorders among minoritized racial/ethnic groups, Rodgers and colleagues (2018) found that overall higher levels of eating disorder symptoms were associated with acculturation stress and appearance ideals. The researchers found evidence that internalization of appearance

standards differed across races and ethnicities and concluded that appearance ideals have been traditionally based on White appearance standards (Rodgers et al., 2018). This ubiquitous model for understanding eating disorder risk has excluded the differences in other idealized body types across races and ethnicities (e.g., hourglass body shape ideal).

Recently, researchers have demonstrated unaccounted for eating disorder risk factors (e.g., discrimination) among marginalized individuals (i.e., lesbian, gay, bisexual, transgender individuals, racial and ethnic minorities, and individuals with obesity; Mason et al., 2021). For example, Mason and colleagues (2021) found a strong link between weight discrimination and eating disorder psychopathology. Although obesity is not an eating disorder, risk of developing AN or symptoms associated with AN (e.g., body weight/shape disturbances, dietary restriction, and compensatory behaviors; APA, 2013) is not far-reaching.

Previous researchers have also addressed the rise in globalization and spread of Western culture as contributing to the rise of eating disorders in non-Western societies (Littlewood, 2004). Although AN is more prevalent among White individuals than Black or Hispanic, it is not a culture-bound syndrome. AN existed before Western culture elevated the thin ideal (Keel & Klump, 2003) and is not bound by class, only affecting White, middle-to-upper class families (Gard & Freeman, 1996). These stereotypes have been disproved by its genetic etiology and historical origins (Keel & Klump, 2003). The prevalence data enumerated above highlight the need for culturally sensitive eating disorder treatment. Unfortunately, the gap in relationally-oriented treatment studies addressing social location factors among AN and non-AN family members persists (later discussed in Chapter 3).

## **Purpose of Dissertation**

The overall aim of this dissertation is to address gaps in relationally oriented treatment studies and recovery research for individuals and their families with AN. In order to address these gaps, a systematic review (see Chapter 3) and original research study (see Chapter 5) were conducted. The following research questions were addressed (see Chapters 3 and 5): “What are the social location, BPSS, and dyadic/family systems outcomes in couple and/or FBTs for AN?”; “How do individuals in recovery from AN experience diet culture? And what are the BPSS experiences of diet culture for individuals in recovery from AN?” The systematic review aimed to better understand how relationally-oriented treatments address the whole health of an individual with AN from a family systems perspective and the original research study aimed to understand how diet culture is biopsychosocial-spiritually experienced by individuals in recovery from AN. Gaining a better understanding of how the totality of health from a dyadic/family systems lens is addressed in relationally oriented treatments and how diet culture is holistically experienced for individuals in recovery will help close the gaps that exist in treatment studies and recovery research.

In order to understand this dissertation in whole, a summary of how each chapter connects is provided. As AN has conceptually evolved over time to include a more robust symptomatology profile inclusive of all aspects of health (i.e., biological/physical, mental, social, and spiritual; see Chapter 2), so have treatment approaches (e.g., systemic and relationally oriented). However, despite progress in the field of AN, integrating all aspects of health into relationally oriented treatment studies lags. A systemic and relational lens is inconsistently apparent in FBTs for AN, social location factors are missing, and physical and mental health outcomes are overemphasized (discussed in Chapter 3). Since gaps in treatment have

implications for recovery, a mixed methods approach was designed to understand an understudied sociocultural factor, namely diet culture, for individuals in recovery from AN (see Chapter 4). According to the original research study—a mixed methods phenomenological study—diet culture overlays health experiences for individuals in recovery from AN and has the potential to be both fueling and oppressive to recovery (see Chapter 5). Healthcare providers working with individuals and/or families with AN or in recovery from AN are encouraged to understand these unique health experiences that go beyond the *DSM-5* markers (APA, 2013; see Chapter 6).

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## CHAPTER 2: THE BIOPSYCHOSOCIAL-SPIRITUAL HEALTH RISKS AND SYMPTOMS OF ANOREXIA NERVOSA

Anorexia nervosa (AN) is a life-threatening biopsychosocial-spiritual (BPSS) illness (Culbert et al., 2015; Stockford et al., 2019) defined by restriction of food intake leading to weight loss, fear of gaining weight or becoming ‘fat’, and significantly low body weight (American Psychiatric Association [APA], 2013). AN is irrespective of social locations (i.e., ages, gender identities, sexual orientation, races, ethnicities, socioeconomic status, and body sizes; National Institute of Mental Health [NIMH], 2017). AN not only adversely affects every bodily system (Mehler & Brown, 2015), it extends beyond in its social (e.g., caregiver burden, interpersonal conflict; Fischer et al., 2015; Fox et al., 2017) and spiritual (i.e., beliefs and values in relation to self, food, eating, and body; Stockford et al., 2019) impact. As such, AN is more than a psychiatric illness, it is a whole health illness.

Accordingly, family-based treatments (FBTs) are oriented to address the systemic and relational health experiences associated with AN, but gaps persist (Fisher et al., 2019). Chapter 3 demonstrated that FBT studies overemphasize physical and mental health outcomes, overlook a relational and systemic orientation in terms of measuring dyadic/family-level change, and underreport social location factors. While it is important not to de-emphasize the role of weight restoration or medical stabilization, there are implications for recovery when treatment gaps persist (e.g., ongoing mental health concerns [Kaye et al., 2008], high risk of relapse [Khalsa et al., 2017]). Unfortunately, the health challenges that individuals in recovery face are tied to the dynamic interplay between personal beliefs, social environment, and cultural norms/values (Bandura, 1986, 1999).

This dynamic interplay means that individuals in recovery are exposed to larger cultural beliefs and values about what it means to be healthy (i.e., diet culture). These include observations of and experiences with food choices, eating patterns, and body movement or physical activity within their environment. As cultural beliefs and values about health and wellness are transmitted through their environment (e.g., social media), they may be particularly harmful—especially those that perpetuate oppressive health beliefs and behaviors (Glaser et al., 2018). Since individuals in recovery from AN continue to struggle with maladaptive beliefs about eating and appearance (Smith et al., 2016), it was critical to understand what role diet culture plays in recovery (see Chapter 5). Given the results from the systematic review (see Chapter 3) and original research study (see Chapter 5), healthcare providers working with individuals and/or families with AN or recovering from AN were encouraged to target interventions to address the full experience of AN and understand the unique dialectical experiences associated with diet culture in recovery (see Chapter 6).

Given the multifactorial etiology and symptomatology of AN and relevant sociocultural risk factors, this chapter aimed to provide a robust and comprehensive understanding of the BPSS health experiences of individuals with AN. The purpose of this chapter was to review the BPSS health experiences (i.e., risk factors and symptomatology) of AN, highlighting the evidence that AN is a whole health illness with family systems implications. The following sections were divided into biological/physical health risks and symptoms, psychological health risks and symptoms, relational health risks and outcomes, sociocultural risks (i.e., social location, diet culture, social media), and spiritual health symptoms. Risk factors were differentiated from symptoms (or outcomes) as depicted in Figures 1 and 2. As shown in Figure 1, diet culture and social location are socially constructed and exist within the sociocultural context. Spiritual

factors were not included in Figure 1 since there is not enough evidence to show how belief systems contribute to the development an eating disorder. As indicated in Figure 2, the internalization of diet culture overlays spiritual health as evidenced by the assimilation of cultural (maladaptive) beliefs and values into one's own belief system (Morris, 2020). Likewise, social location factors overlay spiritual health as evidenced by how a person self-identifies/experiences themselves (e.g., age, gender identity, race, ethnicity, body type; NIMH, 2017). This chapter reviewed each aspect of health associated with AN because being treated as a whole person is important for individuals recovering from AN (Rance et al., 2017). Sociocultural factors are also relevant for individuals recovering from AN, yet understudied experiences. Since gaps in recovery research persist and risk of relapse is high (Khalsa et al., 2017), it was important to also review sociocultural factors associated with AN or risk of AN. Before exploring each domain, it is important to give more context to the sections on relational health risks and outcomes, sociocultural markers, and spiritual health symptoms.

The relational health section gave historical and cultural context to the significant paradigm shift that occurred in the field of eating disorders over a decade ago as it relates to blaming families as opposed to identifying at-risk families and patterns that serve to function as correlational and/or maintenance factors (Le Grange et al., 2010). Relational outcomes were explored from a systemic perspective given the reciprocity of influence between AN and interpersonal dynamics and maintenance of AN within family and couple systems. Next, sociocultural risk factors were further explored as they relate to AN symptomatology and implications for recovery research. Lastly, the chapter ended with a section on spiritual health outcomes, highlighting the foundation of belief and values systems as they pertain to recovery.

## **Anorexia Nervosa: A Biopsychosocial-spiritual Illness**

### **Physical Health Risks and Symptoms**

Before highlighting biological/physical health risks and symptoms associated with AN, it is important to clarify a common misnomer as it relates to AN and ‘anorexia’. Although ‘anorexia’ is defined as ‘loss of appetite’ (Merriam-Webster, n.d.), onset of AN has historically been viewed as a pursuit of self-starvation by suppressing a biological drive for hunger (Bruch, 1982-1983). Loss of appetite does not precede the onset of the illness, rather it may come as a result of food restriction. Understanding why a person or group of people would suppress a biological drive for hunger has compelled researchers over the past few decades to study the genetic epidemiology of this illness (Baker et al., 2017).

### ***Biological/Physical Precursors***

The progression of discovering a biological basis for AN began in the mid-20<sup>th</sup> century with laboratory rat studies (Anand & Brobeck, 1951) to finding neurochemical concordance of AN in monozygotic twin studies (Holland et al., 1984, 1988). These findings led to further research in brain imaging, elucidating the dysregulated serotonergic hormone levels (i.e., altered mood, happiness, a sense of well-being) observed in patients with AN (Treasure & Tiller, 1993). Some researchers have cautioned against the implications drawn from brain imaging studies implying that some observed neurobiological traits may be showing the effect of AN rather than heritability (Kaye et al., 2008). While the heritability of neurobiological traits can be difficult to parse out, researchers have confirmed that body size, specifically body mass index, is heritable (Bulik et al., 2006; Maes et al., 1997). Over 10 years ago, and colleagues (2006) found that low body mass index and greater physical activity were greater among individuals with lifetime AN

as opposed to those without lifetime AN. Within the past five years, researchers found that low body mass index *predicted* AN (Stice et al., 2017).

### ***Physical Symptoms***

The physical symptoms associated with AN pervade every bodily system and range in severity (e.g., brittle hair and nails, anemia, gastrointestinal issues, lanugo, carotenemia, dental erosion, amenorrhea, bradycardia, to name a few; APA, 2013; National Eating Disorders Association [NEDA], 2021). While most physical symptoms are reversible, bone loss is not (Mehler & Brown, 2015). Most concerning are the symptoms that require close medical monitoring as they increase risk for sudden death (e.g., cardiac complications, hypophosphatemia; Gibson et al., 2019). It is vital to understand the physical health implications associated with AN to not only recognize the genetic etiology, but also the severity of symptoms and need for early intervention. In fact, the *Diagnostic and Statistical Manual of Mental Disorders* 5<sup>th</sup> Ed. (DSM-5; APA, 2013) defines AN in both physical and mental health terms: "restriction of energy intake relative to requirements... leading to a significantly low body weight, intense fear of gaining weight or of becoming fat, and marked disturbance in the way in which one's body weight or shape is experienced (p. 338-339)".

### **Psychological Health Risks and Symptoms**

Common psychological traits (i.e., personality traits, temperaments, behavioral tendencies) associated with AN and evidence of their heritability (i.e., genetic influence) are well-documented. These traits include neuroticism (Bulik et al., 2006), perfectionism, negative emotionality (Keel & Forney, 2013), anxiety, depression, obsessionality (Pollice et al., 1997), inhibition, drive for thinness, poor interoceptive awareness (Lilenfield et al., 2006), harm avoidance (Kaye et al., 2004), and cognitive set-shifting difficulties (Holliday et al., 2005). More

often than not, individuals with AN are comorbidly coping with other mental health disorders. Researchers have demonstrated that depressive, anxious, and obsessive-compulsive traits have been observed in childhood (Kaye et al., 2004) and persist following recovery (Anderluh et al., 2003; Holtkamp et al., 2005; Kaye et al., 2008). In fact, one study found that obsessive-compulsive personality traits observed in childhood highly predicted the development of an eating disorder later in life (Anderluh et al., 2003). In addition to tracing personality traits to the development of AN, other psychological indicators include weight control careers (e.g., athletes, models; Wandler, 2012), athletic-ideal, compulsive exercise (Homan, 2010), and dieting, which has been identified as most common symptom onset of AN compared to bulimia nervosa and binge-eating disorder (Hilbert et al., 2014; Stice et al., 2017).

While it can be difficult to parse out risk factors from symptomatology, there are common maladaptive cognitive and behavioral signs and symptoms that are typically associated with AN over the course of the illness. According to the *DSM-5* (APA, 2013), AN is distinguished by two subtypes—restricting and binge-eating/purging—which may crossover during the course of the illness. Common cognitive symptoms include weight/shape/eating concerns, obsessionality with food and physical appearance, body dissatisfaction and dysmorphia, and pursuit of standards of ideal/perfectionism (NEDA, 2021). These are linked to behavioral symptoms such as dieting, fasting, food restriction/avoidance, food rules/rigidity, body/weight checking, compensatory behaviors (e.g., self-induced vomiting, misuse of laxatives, diuretics, over or compulsive exercising), and nonsuicidal self-injury (NEDA, 2021). As mentioned previously, some of these psychological factors precede onset of full syndrome AN (e.g., compensatory behaviors, drive for thinness, body dissatisfaction, mental health conditions), and therefore, are best understood in context of the whole AN experience. It is worth mentioning

that although the enumerated psychological traits have been associated with adverse health outcomes, they are not inherently pathological or consistently associated with negative health outcomes (e.g., perfectionism and hope/motivation/achievement; Stoeber & Rambow, 2007). As demonstrated, behaviors and cognitions influence functionality and health—including relational health.

### **Relational Health Risks and Outcomes**

The link between mental and relational (i.e., family dynamics, psychosocial, social environment) health is less clear. Over 30 years ago, families were regarded as contributing to the development of AN (e.g., anorexogenic or anorectic family; Crisp, 1977; Minuchin et al., 1975, 1978; Schmidt, 2003). During the 70s and 80s, researchers began to report common characteristics associated with AN such as low family cohesion, poor communication (Leon et al., 1994), high conflict/poor conflict resolution (Kog & Vandereycken, 1989; Strober & Humphrey, 1987), and low emotive expression (Dare et al., 1994; Strober & Humphrey, 1987). If not clearly stated, then these common family characteristics could be misconstrued as causative as opposed to risk or maintenance factors. These are not trivial differences. Indeed, past researchers questioned the validity of the family causality model and brought attention to the “dysfunction” or distress observed in family dynamics *as a result of AN* (Bruch, 1978; Lacey & Price, 2004), implying that families should not be blamed for their child’s mental health illness. Nonetheless, a pattern of stigmatizing families, specifically mothers, found its way in the scientific literature (e.g., Becker et al., 1981; Haggerty, 1983).

Compared to today, the cultural climate of the 60s and 70s was not as sensitive to language and labels (e.g., the anorectic or psychosomatic family). Although the effect of the application of Minuchin et al.’s (1975, 1978) psychosomatic family model to families is

unknown, there is evidence of the impact on family stigma (Corrigan & Miller, 2004). A pattern of blaming and shaming families for the etiology of a psychiatric illness is oppressive (Corrigan & Miller, 2004). Many may recall the public stigma associated with the "schizophrenogenic mother" (Neill, 1990) who was blamed for her child's psychiatric illness. Now, eating disorder professionals are opposed to blaming families—over 10 years ago, the Academy of Eating Disorders took a position against any etiological model that viewed the family as contributing to an eating disorder (Le Grange et al., 2010). Current researchers examining family dynamics seek to understand risk factors and their role in the maintenance of symptoms. This paradigm shift in understanding family risk factors—as opposed to causal factors—is crucial, given that eating disorder providers seek to empower families and work to reduce feelings of shame and blame in families.

Within the past couple decades, researchers have added to the literature in the link between AN and relational health risks. For example, parental dynamics and family environment factors can function to maintain AN symptomatology, and therefore, impact treatment outcomes. Previous researchers have found that the presence/absence of expressed emotions (i.e., critical comments, hostility, positive remarks, warmth, and emotional over-involvement) from parents/caregivers have been associated with FBT outcomes (Allan et al., 2018; Philip et al., 2020; Rienecke et al., 2016). For example, while Le Grange et al. (2011) found that warmth predicted good treatment outcomes, Rienecke et al. (2016) found no treatment effects on eating disorder outcomes despite the presence of warmth and positive remarks. By contrast, Rienecke and colleagues (2016) found that paternal criticism and maternal hostility resulted in less improvement in treatment. Philip and colleagues (2020) found that lower caregiver skills, higher impact of AN symptoms, higher levels of depression, and motivation to change in caregivers

significantly predicted higher levels of expressed emotion. Hoste and colleagues (2012) studied expressed emotion among White as well as racial and ethnic minoritized families with AN and found no difference in the families with high expressed emotion. However, they found that White families were higher on warmth and positive remarks than minoritized families (Hoste et al., 2012).

Psychosocial (i.e., interplay of cognitive, behavioral, and relational dynamics) experiences can increase risk and contribute to symptoms of AN. The interplay of psychological traits (e.g., perfectionism, negative emotionality, weight concerns), weight, and appearance-based teasing from the social/relational environment (e.g., peers, teachers, coaches, parents, siblings) are known to increase risk for eating disorders such as AN (Keel & Forney, 2013). Weight-related teasing has been specifically associated with disordered eating behaviors such as dietary restraint and compensatory behaviors and appearance-based teasing has been associated with body dissatisfaction (Menzel et al., 2010). In a recent case-control study comparing AN with bulimia nervosa, women with AN were significantly more likely to not only report a family history of eating disorder, perfectionism, and unresolved family conflict, but also parental comments and teasing related to eating, appearance, and weight/shape (Machado et al., 2016). In addition to family weight-teasing, researchers have also found evidence for parent weight talk (e.g., comments about own weight and encouragement of dieting), mother dieting (Neumark-Sztainer et al., 2010), and family transitions (e.g., school transitions, death of a family member, relationship changes, home and job transitions, illness/hospitalization; Berge et al., 2012) on disordered eating/eating disorder development.

Researchers have also studied the effects of childhood maltreatment (e.g., emotional abuse, neglect, and/or exposure to intimate partner violence) on AN symptomatology. For

example, researchers recently found that adults who retrospectively reported any maltreatment and physical and sexual abuse reported significantly more symptoms of AN than those who did not (Talmon & Widom, 2021). Other researchers have found a link between emotional childhood maltreatment and AN symptomatology indicating a strong relationship with weight concern, negative self-image, and maladaptive emotional response (Rai et al., 2019). Rai et al. (2019) concluded that emotional dysregulation mediates the effects of emotional childhood maltreatment and symptoms of AN and is strongly correlated to long-term morbidity in individuals with AN (Rai et al., 2019). Not only are there known relational health risk factors, AN is a burdensome illness with known relational outcomes.

### ***Relational Outcomes: Family***

The effect of AN on families creates a disruption on overall family functioning, including patterns of relating/interacting. This disruption includes caring for a child or spouse/partner with an eating disorder, which can be a burdensome and stressful experience (Smillie & Felton, 2017)—permeating mental, emotional, physical, social, and financial aspects (McCormack & McCann, 2015). Caring for a loved one with an eating disorder has been associated with more tense home environments such as increased conflict, stress, anger, disagreements, problematic communication, difficulty around meal/food planning (Dick et al., 2013; Smillie & Felton, 2017). Caregivers (or close family members) have reported experiencing guilt and distress after discovering the eating disorder (Fox et al., 2017). One meta-synthesis of studies highlighted patterns of overlooking caregivers and siblings needs in treatment and research (Fox et al., 2017). Indeed, there are systemic outcomes within the family system such as communication difficulties, caregiver burdens, interpersonal distress, and increased conflict around meals/food.

### ***Relational Outcomes: Couple***

Despite the paucity, there is growing empirical support highlighting the interpersonal distress and relational strain caused by AN on romantic partnerships. For example, Fischer et al. (2015) described how the interpersonal distress for couples experiencing AN is dependent on many factors such as perception of negative consequences, motivation to change, and partner's change promotion and validation/acceptance. Antoine and colleagues (2018) illuminated the dyadic and phenomenological experience of living with AN as a couple. They described compromised intimacy, daily conflict around food and body issues, and dysfunctional patterns and roles that served to maintain the illness (Antoine et al., 2018). Other researchers have demonstrated similar findings as it relates to eating disorders in general such as decreased emotional and sexual intimacy, loss of shared routine activities, and different expectations about recovery (Dick et al., 2013). Some researchers have also found that non-eating disorder partners may experience pressure and responsibility to monitor behaviors (Linville et al. 2016). Linville and colleagues (2016) also highlighted the reciprocal dynamics that exist among couples with one partner who has an eating disorder. Their team found that more relational stability was associated with less eating disorder symptoms and less relational stability was associated with more eating disorder symptoms (Linville et al., 2016). Less is known regarding dyadic/couple experiences of living with AN. Fischer et al. (2015) described non-eating disorder partner's behaviors in context of AN and Antoine and colleagues (2018) illuminated the dyadic and phenomenological experience of living with AN as a couple.

In sum, the enumerated health risk factors and outcomes associated with AN highlight its whole health impact. In light of the BPSS experience of AN, the risk factors, symptoms, and outcomes are conceptualized in Figures 1 and 2. Sociocultural risk factors are both fixed and

variable markers of etiology and difficult to parse out between eating disorder diagnoses (Weissman, 2019). According to Weissman (2019), parsing out eating disorder-specific sociocultural risk factors is important to understand eating disorder etiology, especially given the evidence of risk factors that are either diagnosis-specific (e.g., low body mass index predicting AN) or transdiagnostic (i.e., any eating disorder; body dissatisfaction, weight concerns, child maltreatment; Weissman, 2019). However, due to the literature gap in disorder-specific sociocultural risk factors (Weissman, 2019), the following section highlighted relevant sociocultural factors as they relate to AN symptomatology (as opposed to a diagnosis of AN) and implications for recovery research.

### **Sociocultural Risk Factors**

#### **Social Location**

Although less attention has been given to social location indicators as they relate to AN, previous researchers have highlighted the prevalence of disordered eating/eating disorders across social locations. While treatment studies skew toward females (Raevuori et al., 2014), eating disorders are becoming more recognized among males (Weltzin et al., 2012), in part due to increasing research as a result of the sex-neutral criteria in the *DSM-5* (APA, 2013; Raevuori et al., 2014). Gender identity may function as a risk factor for AN since researchers have demonstrated that transgender youth have a four times higher rate of disordered eating than their cisgender peers (Diemer et al., 2015). Moreover, gender nonconforming individuals with a female assigned sex at birth have a heightened lifetime risk of eating disorders relative to male-to-female individuals (Diemer et al., 2018). These staggering findings corroborate the co-occurrence of body discontentment/drive for body ideals and gender dysphoria (Strandjord et al., 2015).

Other researchers have demonstrated the link between discrimination and eating disorder psychopathology among marginalized individuals (i.e., lesbian, gay, bisexual, transgender individuals, racial and ethnic minorities, and individuals with obesity; Mason et al., 2021). Weight discrimination for individuals with obesity was the strongest link—indicating risk of developing AN or symptoms associated with AN (e.g., body weight/shape disturbances, dietary restriction, and compensatory behaviors; APA, 2013) is not far-reaching for individuals with larger body sizes. Although lifetime AN is lower among non-Hispanic Black and Hispanic than White individuals (Udo & Grilo, 2018), likelihood of ever seeking treatment for an eating disorder is significantly lower for racial/ethnic minoritized groups (Coffino et al., 2019). This may account for the underrepresentation of racially and ethnically minoritized groups in FBT studies for AN (later discussed in Chapter 3).

Though eating disorder markers may differ across racial and ethnic groups, there are some shared risk factors across social locations. For example, African American women with low ethnic identity were at higher risk for eating pathology (i.e., binge eating and bulimic behaviors) compared to White non-Hispanic women with high ethnic identity (Shuttlesworth & Zotter, 2011). According to a more recent population-based study of 2,793 adolescent females, disordered eating behaviors were more common among adolescents with overweight compared to those without across all racial/ethnic groups (i.e., White, Hispanic, Black, and Asian; Rodgers et al., 2017). However, prevalence of disordered eating among Asian female adolescents was highest compared to Black, Hispanic, and White female adolescents (Rodgers et al., 2017). Another study found that higher levels of eating disorder symptoms were associated with acculturation stress and appearance ideals for racial/ethnic minoritized groups (Rodgers et al., 2018). These researchers discovered that internalization of appearance standards differed across

racess and ethnicities (e.g., thin- or muscular-ideal verses hourglass shape ideal), suggesting that appearance ideals have been traditionally based on White appearance standards (Rodgers et al., 2018). Though treatment studies for AN are skewed toward certain demographics (e.g., White female adolescents), previous researchers have dismantled the stereotype that AN only impacts White, middle-to-upper class families (Gard & Freeman, 1996). Indeed, risk of disordered eating/eating disorders, including AN, is present in diverse social locations. Social location is a multifaceted construct that also overlaps with societal ideals, cultural values, and beliefs about health and wellness (e.g., appearance ideals and race/ethnicity; Rodgers et al., 2018). This includes diet culture—a relevant sociocultural risk factor for AN.

### **Diet Culture**

Diet culture has been recognized as a system of beliefs, values, and meanings that promotes physical health by equating thinness, muscularity, and particular body shapes, food choices, and eating behaviors with morality (Harrison, 2018; Morris, 2020). While the concept of ‘diet culture’ has become more well-known within the past few years, the scientific study of ‘diet culture’ is very new (Davidson, 2020; Morris, 2020). Although following a diet is a less popular concept among U.S. consumers, American society is steeped in diet culture (Harrison, 2019; Trollope-Kumar, 2020), which has forced the dieting industry to shift toward selling “health and wellness” (Chen, 2016). As one author noted, “You don’t have to be following a diet to be a part of diet culture. It’s endemic to Western culture” (Harrison, 2018). Diet culture shows up in Western culture through the “Eat Clean” movement (“good” versus “bad” food), fad diets (e.g., intermittent fasting), nutrition programs, diet products, weight-loss businesses, and physical fitness training programs (Trollope-Kumar, 2020).

Diet culture is an oppressive system—grounded in beliefs and values about health and wellness that promote weight loss in order to achieve a higher status (Harrison, 2018). This system elevates individuals with thin bodies (thin privilege) and pathologizes (fat shames) individuals with larger bodies. Diet culture also perpetuates maladaptive beliefs about nutrition and physical activity (National Institute of Diabetes and Digestive and Kidney Diseases, 2017) by encouraging external rules of what, when, and how much to eat, pathologizing larger bodies, and implying physical activity as punishment for or prevention of becoming fat (Chastain, 2019). Unfortunately, when diet culture beliefs and values become one’s own beliefs and values, there are significant health implications. One study found that internalization of diet culture (i.e., accepting broader cultural beliefs and standards of eating practices and physical appearance as one’s own; Morris, 2020) was associated with disordered eating, thin idealization, weight bias internalization, body shame, body dissatisfaction, and inflexible views of beauty.

Although there are anti-diet culture advocates on social media working to challenge the beliefs and values perpetuated by diet culture (James, 2020), harmful online content relevant to eating disorders continues to exist (e.g., pro-anorexia websites; Christodoulou, 2012; Saul & Rodgers, 2018). According to a recent report, companies promoting weight loss will need to begin using social media and influencers to reach Generation Z—the future generation of dieters (LaRosa, 2019).

## **Social Media**

Over 80% of adults (ages 18-49) in the United States use social media, a trend that has remained relatively stable over the past five years (Pew Research Center, 2021). In 2018, 95% of teenagers used smartphones and 45% of them were online ‘almost constantly’ (Pew Research Center, 2018). Trends in social media usage among adults have also increased in the U.S. over

the past decade (Perrin, 2015)—roughly 65% of whites, 65% of Hispanic/Latinos, and 56% of African Americans use social media. The effects of social media on mental health can be both positive and negative (Sharma et al., 2020). Although less than 12% of teenagers think social media can adversely impact mental health (Pew Research Center, 2018), researchers have shown that excessive social media use is associated with negative mental health outcomes (e.g., anxiety, depression, eating concerns, body dissatisfaction, poor self-esteem, social comparison; Glaser et al., 2018; Sherlock & Wagstaff, 2019; Sidani et al., 2016).

Social media is more than social networking; it serves as a transmitter of health information (Perrin, 2015), such as diet culture beliefs and values. As health information—both helpful and harmful—gets passed through media channels, content can become internalized (i.e., accepting other beliefs and values as one’s own). Social media platforms have served as a channel for promoting messages about health and wellness (Olof Lagrosen & Grundén, 2014; Powell et al., 2011), which have been driven by the values and beliefs associated with diet culture (i.e., a system of knowledge, values, and meanings that elevates health choices by attaching morality to food choices, eating behaviors, and physical appearance; Morris, 2020). Internalizing broader cultural beliefs and values about health and wellness has been associated with higher levels of disordered eating and body image concerns (Davidson, 2020).

Since diet culture beliefs and values are transmitted through social media, it is no surprise that social media influences body-related social comparison and body dissatisfaction (Fardouly & Vartanian, 2016). Researchers have found a strong relationship between body-related social comparison and disordered eating (Hamel et al., 2012). In fact, body-related social comparison predicted AN symptomatology (i.e., drive for thinness and body dissatisfaction) even when controlling for self-esteem and depressive symptoms (Hamel et al., 2012). Undoubtedly, social

media not only serves to distribute health information (Perrin, 2015) but also as a platform for marketing (Powell et al., 2011) in order to promote businesses such as the wellness industry (Olof Lagrosen & Grundén, 2014). Due to the public health epidemic on obesity (Hales et al., 2020), the wellness industry has profited from a societal focus on physical health (e.g., dieting and exercise) as the epitome of what it means to be healthy. Given this societal focus and online platform, researchers have found that social media use is associated with eating disorder symptoms.

Previous researchers have demonstrated the association with disordered eating and body image concerns associated with social media use and platforms. For example, Rodgers et al. (2020) found that social media use among both adolescent males and females was associated with internalization of the social media ideal (models) and internalization of muscular ideal, muscle building behaviors, dietary restraint, appearance comparison, and body dissatisfaction. Although the variability explained by their models was less robust for males than for females, Rodgers et al. (2020) offer evidence linking social media use to body image, eating, and muscle building among adolescent males. Wilksch et al. (2020) found that Snapchat and Tumblr were associated with significantly higher levels of disordered eating cognitions for adolescent girls, whereas all social networking sites (SNS; i.e., Facebook, Instagram, Snapchat, Tumblr) were associated with higher levels of disordered eating cognitions for adolescent boys.

Overall, disordered eating behaviors (i.e., skipped meals, ate very little food, rigid meal plan, vomiting, strict exercising, bingeing) increased as the number of social media accounts a person had increased (2 or 3-4), but decreased when a person had fewer accounts (0-2). The more time spent on social media, the higher the eating disorder cognitions and behaviors. Saunders and Eaton (2018) examined the relationship between SNS (Facebook, Instagram, and

Snapchat), body dissatisfaction, and disordered eating among young women (aged 18-24 years). Levels of disordered eating differed across the sites, but upward body comparison (i.e., comparing self to physically attractive people), body dissatisfaction, and disordered eating (i.e., bingeing, purging, cognitive restraint) were associated with all sites. Body dissatisfaction and excessive exercise were also significantly associated across all sites. Aparicio-Martinez et al. (2019) investigated the relationship between disordered eating and sociocultural factors among college-aged women. They found that 93% of the women desired to change at least three areas of their body through physical activity (92%), diet (48%), surgery (24%), and beauty products (23%). Disordered eating attitudes were positively associated with addiction to SNS, and addiction to SNS was significantly correlated with the number of methods used to change body image, thin body ideal, and lower self-esteem. Within social media are trends that are known to be linked to eating and body concerns—fitspiration and thinspiration.

### ***Fitspiration/Thinspiration***

Within the past few years, fitspiration (#fitspo) has become an online trend in promoting healthier living by inspiring individuals to eat healthy and exercise, whereas thinspiration (#thinspo) focuses on thinness and eating disorders/disordered eating. Individuals directly interact with fitspiration and thinspiration content through SNS. Businesses and organizations send more fitspiration content whereas individuals send more thinspiration content (Harris et al., 2018). Both have become particularly harmful for perpetuating the thin or muscular ideal and increasing body dissatisfaction. For example, Harris et al., (2018) found that 67.2% of #thinspo and #fitspo tweets on Twitter were related to body image, fitness, food, dieting, or eating disorders. Not only were #thinspo tweets sending images of extremely thin women, users were retweeting and liking #thinspo tweets more than for #fitspo. Another study found that viewing

fitspiration images on Instagram among female undergraduate students increased negative mood and body dissatisfaction (Tiggemann & Zaccardo, 2015). Carrotte et al. (2017) compared fitspiration body image portrayals for males and females across Instagram, Facebook, Twitter, and Tumblr. They found that most posts tagged #fitspo were on Instagram and either related to exercise (74.2%) or food (19.6%), and the majority adhered to the thin or muscular ideal (i.e., female bodies were thinner, but toned, and males were more muscular). Compared to fitspiration, thinspiration images show more body parts and reference mental illness (e.g., eating disorders, depression, or suicidality; Alberga et al., 2018). Regardless, both fitspiration and thinspiration content focus on appearance, sexually suggestive images, and restrictive eating, elevating a fit-and-thin body ideal (Alberga et al., 2018). This corroborated with Boepple and Thompson's (2016) findings that both thinspiration and fitspiration websites promoted objectification, guilt-induced messages about body/weight, weight stigmatization, and dieting or restrictive eating. Jennings et al. (2020) study found that fitspiration and thinspiration images elicited significantly less positive emotion than the control images among individuals with or without a history of disordered eating. For those with a history of disordered eating, fitspiration content produced more positive emotions and social comparisons (e.g., fatter, skinnier) whereas thinspiration (e.g., pro-Anorexia) content induced anxious emotions. Individuals that frequently interact with media focused on weight, shape, or eating not only receive contradictory messages, but are at higher risk for eating disorders.

### ***Media Messages and Literacy***

Media messages about eating and the body have been contradictory, but increasing media or health literacy may be helpful in reducing body concerns. One study explored the conflicting mass media messages on eating and the body, relating the contradictory food-related media

marketing to schizophrenic (double-bind) communication (Forgács et al., 2018). They identified five main categories for media messages over the last century: “1) Be thin!; 2) Consume and eat!; 3) Be afraid of food!; 4) Food will disappear!; 5) You are not feminine/masculine enough!” (p. 402). They argued that mass media has replaced the caregiver’s role – prescribing a thin body while encouraging eating—and extrapolate this to AN, orthorexia, and bulimia. Demonstrating how media marketing influences consumers unconsciously, they contend that any “rational suggestions from the health industry... are incapable of overwriting this psychological level” (p. 410). To counter this insidious effect on consumers, Forgacs et al. (2018) believe healthcare and scientists need to use the power of media and technology to improve mass communication on healthy eating.

Previous researchers have also studied media literacy as it relates to eating disorder symptoms. According to recent systematic reviews, researchers found that media literacy interventions significantly reduced shape and weight concerns for both females and males (Le et al., 2017), but not disordered eating due to the lack of programs targeting eating outcomes (McLean et al., 2016). McLean and colleagues (2016) also found media skepticism (i.e., recognizing that media messages and images distort reality) were associated with lower body concerns. By contrast, they found consistent results between high media attention to body image and/or eating content and internalization of thin/media ideal and higher levels of body and eating concerns. As these enumerated findings demonstrate, social media usage and content have been associated with eating disorder-specific symptoms, and media literacy or skepticism can help reduce symptoms.

In sum, sociocultural risk factors are prevalent in Western society, but not everyone who identifies with higher risk social locations (e.g., transgender, White or Asian, or female) or

exposed to these factors (e.g., diet culture, social media) will develop an eating disorder. Rather, when biological/physical, psychological, relational, and sociocultural risk factors are combined, their complex interactional influences contribute to the development of AN. While there is need for further research, the overlay of sociocultural factors has spiritual health implications for individuals in recovery from AN. The BPS experience of AN and spirituality are not mutually exclusive. As such, the next section will highlight spiritual health symptoms.

### **Spiritual Health Symptoms**

Spiritual symptoms associated with AN includes a *loss* of sense of self or identity, values, and healthful beliefs regarding food choices, eating behaviors, and physical appearance that can impede treatment and recovery. Most notably, AN has been characterized as more than just an illness but also an identity (Rich, 2006). Previous researchers have demonstrated this particular spiritual health impact on individuals by highlighting spiritual symptoms associated with AN. For example, individuals in recovery from AN have reported that it took over their ‘real selves’ (Williams et al., 2016) or obtained control (Williams & Reid, 2012), and became part of or completely changed their identity (Stockford et al., 2019; Williams et al., 2016; Williams & Reid, 2012). For some, AN served as a tool to avoid coping with negative emotions and recovery consisted of addressing the anorexic voice and developing a new sense of self (Williams & Reid, 2012). For women with lifetime AN, the taking over of their ‘real selves’ served to not only maintain the illness, but also fueled their fear of letting go of the illness and “being no one without AN”, which in turn disconnected/detached them from others—keeping them invisible (Williams et al., 2016). They compared AN to an abusive relationship in which they experienced two selves embedded within their view of self (Williams et al., 2016). Recovery included discovering their real self, accepting the fear of the unknown, and separating the self from AN.

Stockford and colleagues (2019) systematically reviewed literature on women's recovery from AN and synthesized the process of recovery into stages of experiencing AN, turning point from AN, and recovery as reclamation of self. Experiencing AN was conceptualized as fragmented selves, AN as part of their identity, no sense of self, and powerlessness in relationships. The reclamation of self (or process of recovery) consisted of meaningful relationships, building a new identity (inclusive of self-worth and self-efficacy), changing values, and self-acceptance.

Others have also identified the need to separate from AN, rediscover their sense of self, change values, and address maladaptive beliefs about eating and appearance as facilitative to their recovery process (Smith et al., 2016). Part of recovery is addressing beliefs and perceptions about body weight changes, as one participant in a previous study stated: "Gaining weight does not mean becoming fat, but instead results in increased confidence" (Smethurst & Kuss, 2018, p. 1293). Some have reported that societal ideals/expectations and the anorexic voice/dual identity have served as barriers to recovery whereas changing values/perspectives have been important processes to facilitating recovery (Smethurst & Kuss, 2018). Being in recovery allowed them to evaluate the impact of AN on their values and how AN restricted them from pursuing a meaningful life. These same individuals also identified interpersonal connections with friends and family and supporting healthy eating as facilitative to recovery.

Other researchers have explored the lived experiences of treatment and recovery for adolescents (aged 10-23 years) with AN (Bezance & Holliday, 2013). A couple key themes that were found had to do with the effects of inpatient treatment on identity development and recovery. Overall, the authors found mixed experiences, but most notable was the emphasis on physical treatment feeling neglectful of psychological factors (e.g., self-esteem, control, emotion regulation), resulting in a loss of identity. As the authors concluded, "...inpatient practices can

inadvertently reinforce some of the key features of AN and hinder adolescents' own developmental trajectory by reducing the opportunity for identity development" (Bezance & Holliday, 2013, p. 358). These enumerated accounts give voice to the individuals who have not only experienced AN but also fight to recover from it. This section also underscores the need to address spiritual health as it relates to treatment and relapse prevention due to the significant spiritual health implications associated with AN.

Needless to say, the enumerated health risks and symptoms associated with AN profoundly impair physical, mental/emotional, relational, and spiritual well-being. Not only is mental health as important as physical health, so are relational and spiritual health. Since there is evidence of BPSS markers, the totality of health needs to be addressed for intervention and relapse prevention purposes. If treatment models overvalue physical and mental health, then other health experiences will be overlooked. When core beliefs and value systems are compromised as a result of AN, the implications for recovery and relapse prevention are significant. Understanding AN as a BPSS illness allows health professionals to elevate each domain of health and think systemically and holistically about AN from development to treatment and recovery.

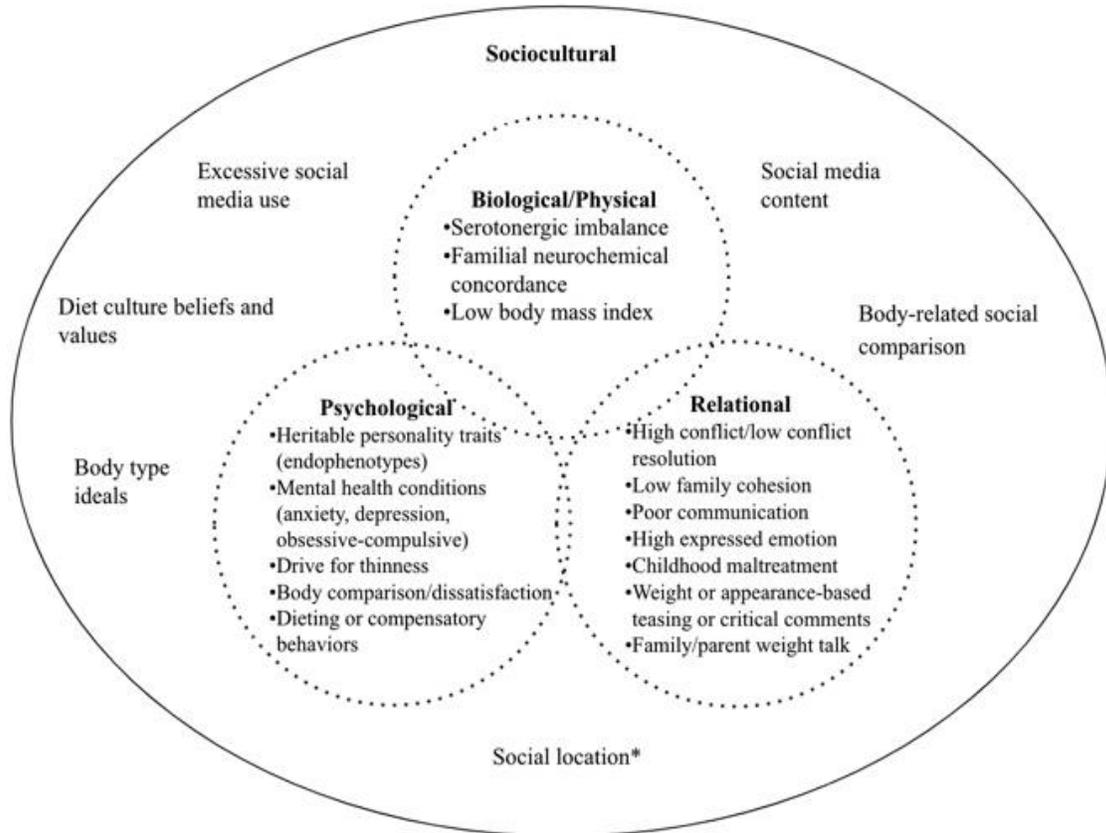
### **Conclusion**

This chapter provided a comprehensive overview of the BPS etiological model of AN (Culbert et al., 2015), including relevant sociocultural risk factors, and its BPSS health impact. Since AN also compromises relational and spiritual health, positive health change should not be limited to physical (e.g., weight restoration) and psychological (e.g., reduction in eating disorder cognitions and behaviors) outcomes. Given the risks associated with social location, diet culture, and social media, it is important to gain a better understanding of these risk factors and how they

overlap with AN—from treatment to recovery. AN is a tenacious whole health illness not limited by stereotypical social locations (e.g., White female adolescent) and known to have persistent symptoms that can impede recovery and increase risk for relapse. Therefore, the next chapter will systematically review the literature to explore how FBTs are addressing AN as a BPSS illness from a systemic and relational lens.

**Figure 1**

*Biopsychosocial-spiritual Risk Factors of Anorexia Nervosa*

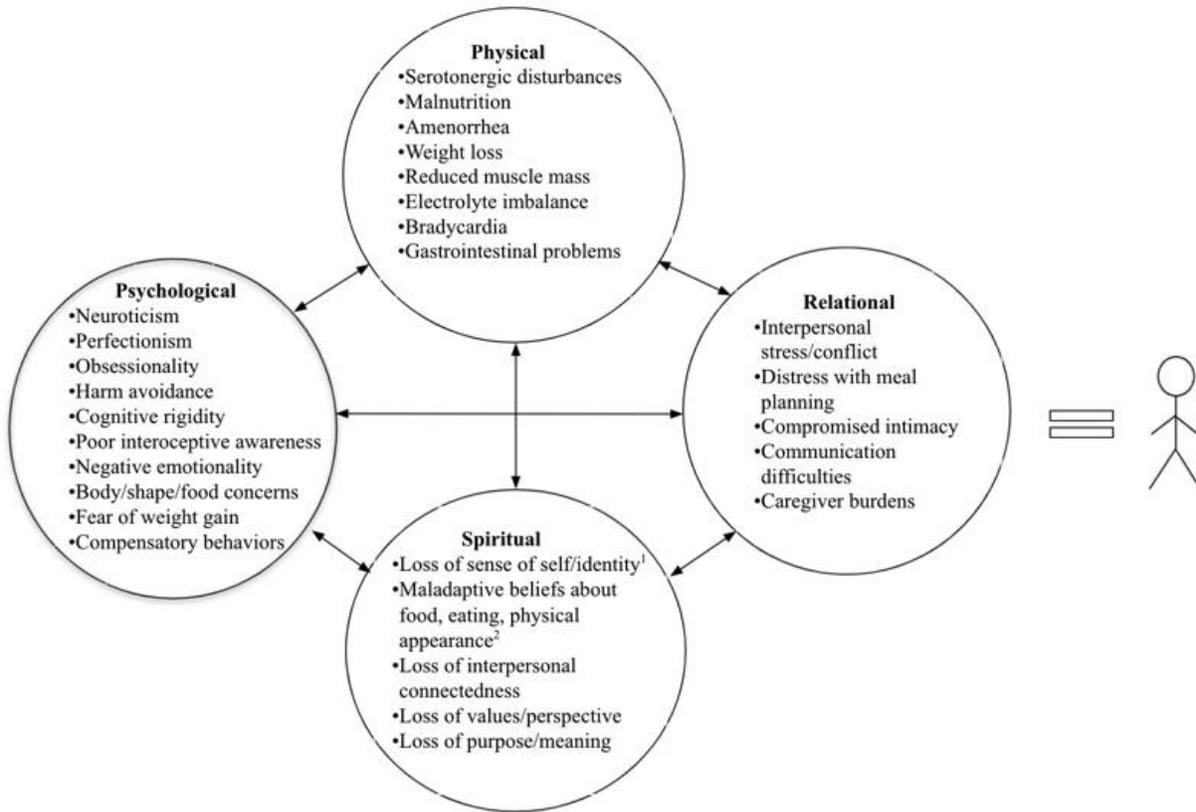


*Note.* Dotted lines represent the permeability of the health domains and how the larger sociocultural environment overlays the whole person.

\*Refers to unique risks associated with social location

**Figure 2**

*Biopsychosocial-spiritual Symptoms and Outcomes of Anorexia Nervosa*



<sup>1</sup>Includes social location (e.g., age, gender identity, race, ethnicity, etc.)

<sup>2</sup>Includes internalization of diet culture

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## CHAPTER 3: THE MIND, BODY, SPIRIT, AND FAMILY OF FAMILY-BASED TREATMENTS FOR ANOREXIA NERVOSA: A SYSTEMATIC REVIEW

Eating disorders, including anorexia nervosa (AN), are steadily increasing on a global scale (Galmiche et al., 2019) and nearly 28.8 million people alive in the United States in 2018-19 will have an eating disorder at some point during their life (Deloitte Access Economics, 2020). AN—the focus of this study—is a life-threatening biopsychosocial-spiritual (BPSS) illness (Culbert et al., 2015; Williams et al., 2016) defined by restriction of energy intake relative to requirements leading to significantly low body weight, intense fear of gaining weight or becoming ‘fat’, and body weight or shape disturbance (American Psychiatric Association [APA], 2013). AN has one of the highest mortality rates—six times that of their healthy peers (Fichter & Quadflieg, 2016), and suicide risk rates of all mental health disorders, second only to opioid addiction (Chesney et al., 2014). Unfortunately, risk of relapse continues to be high within the first year following treatment (Khalsa et al., 2017) and recent evidence suggests that a minority of patients with AN may fully recover (Franko et al., 2018).

AN is irrespective of social location (i.e., age, gender identity, sexual orientation, race, ethnicity, socioeconomic status, religious orientation, and ability status; National Institute of Mental Health, 2017). Prevalence of disordered eating—a risk factor for AN—is increasing across diverse social locations. Population-based studies have shown that Asian female adolescents report higher rates of disordered eating compared to Black, Hispanic, and White female adolescents (Rodgers et al., 2017) and transgender youth have a four times higher rate of disordered eating than their cisgender peers (Diemer et al., 2015). Unique eating disorder risks exist among religious/non-religious groups (Wilhelm et al., 2018) and individuals with physical

limitations (Taleporos & McCabe, 2002). Despite rising prevalence among males (Weltzin et al., 2012), treatment studies skew toward non-Hispanic, White women (Coffino et al., 2019).

AN is not only a complex (and sometimes chronic) illness, it is also treatment resistant and egosyntonic in nature (Gregertsen et al., 2017). Fortunately, family-based treatments (FBTs) for AN have a well-established evidence base (Lock, 2019) and couple-based interventions for AN are growing and gaining empirical support (Baucom et al., 2017; Schmidt et al., 2015). Since weight restoration is critical for reversing the physical health effects of AN (Mehler & Brown, 2015), treatment tends to focus on food and weight (Rance et al., 2017). However, women in recovery have reported that an overemphasis on food and weight is unhelpful and prefer to be seen and treated as a whole person (Rance et al., 2017). A metasynthesis study found that health professionals treating individuals with AN focus more on the physical state of the patient (i.e., condition of body, weight, and behavior), which diverges from the patients' experiences of AN (i.e., psychologically and relationally distressing; Sibeoni et al., 2017). Underscoring this disparity is the process of recovery, which includes relational (i.e., meaningful relationships) and spiritual (i.e., new sense of self/identity, altered belief and value systems) components (Stockford et al., 2019). Gaps in treatment can have long-lasting implications for individuals battling AN, resulting in growing mental health complications (Kaye et al., 2008), challenging relational dynamics (Linville et al., 2012), and faltering spiritual health (i.e., loss of sense of self/identity; Williams et al., 2016).

The prevalence and mortality rates reveal that AN is a severe illness impacting individuals and families and risk of AN is not limited to certain social locations (e.g., White female adolescents). To date, only one study has shown that a manualized approach of FBT (i.e., Maudsley model; Lock & Le Grange, 2013) is effective in treating the *whole person* with AN

(i.e., physical, mental, social, and spiritual health; Wallis et al., 2017). It is unknown how FBTs and couple-based treatments address the whole person with AN from a relational (i.e., dyadic/family) lens. In light of the high risk of relapse following treatment (Khalsa et al., 2017), it is important to understand how the full experience of AN is being addressed in relationally based treatments (i.e., couple and/or FBTs). Theory grounded and guided the basis for this current study.

### **Theoretical Orientation**

In the late 70s, an American psychiatrist named George Engel (1977, 1980) called for the replacement of the traditional biomedical model for a more relational and systems-based model, namely the biopsychosocial model. Grounded in general system theory (von Bertalanffy, 1968), Engel argued for scientists and providers alike to take into account multiple systems (i.e., community, family, two-person, person, nervous system, organ system, tissue, cell, and molecule) for a more holistic and patient-centered approach. Further, Wright and colleagues (1996) contended for spirituality (i.e., health beliefs) to be included in healthcare settings to help families cope with disability and/or illness. Over time, this became known as the BPSS framework (Engel, 1977; 1980; Wright et al., 1996). This framework highlights the experience of AN and systemic effect of AN on health, including couple/family systems.

As a family health concern, AN was originally treated by family therapists grounded in family systems theory (FST; Dare & Eisler, 1997; Minuchin et al., 1975; Selvini Palazzoli, 1974; Wynne, 1980). FST is also based in general system theory (von Bertalanffy, 1968) and is grounded in the belief that families are organized wholes with interdependent subsystems (Minuchin, 1985). Major tenets of FST include reciprocal causality, homeostasis, open systems, and understanding families in sociocultural context (Hecker et al., 2003). Family therapists avoid

pathologizing or blaming one family member for a behavior or condition, rather look at how patterns of relating/interacting contribute to or maintain symptomatic behaviors (Hecker et al., 2003). Family systems theorists elevate the role of the family in treatment by targeting interventions at the family-level (e.g., dyadic or triadic dynamics) and believe sustainable change is achieved when families can adapt to new ways of relating/interacting. As such, positive change is measured systemically (e.g., multiple perspectives), not individually. Grounded in FST, FBTs are able to address the full experience of AN (i.e., BPSS) as well as the patterns sustaining the illness (e.g., parent-child dynamics, child-environment interplay).

### **Purpose of the Present Study**

FBTs aim to address multiple factors (e.g., physical, psychological, and social) that influence and maintain AN. Though FBTs are the most well-established treatments for adolescent AN (Lock, 2019), there are gaps that need to be addressed. With the rising global prevalence rates of disordered eating and eating disorders, including AN, it is unknown if relationally-oriented treatment studies reflect a diverse population. This current study aims to (1) shed light on how social location factors are addressed (i.e., assessed and analyzed) and (2) gain a better understanding of the gap between the BPSS experience of AN and treatment outcomes in relationally oriented treatment studies. A systematic review was designed to address these aims and asked the following research question: “What are the social location, BPSS, and dyadic/family systems outcomes in couple and/or FBTs for AN?”

## **Methods**

### **Search Strategy and Eligibility Criteria**

Three search engines that are known to capture physical, psychological, and social research were used: PubMed, PsycINFO, and CINAHL (see Table 1). ‘FBT’ was operationally

defined as family involvement in the intervention. Studies were included if (1) the sample included children, adolescents, and/or adults diagnosed with anorexia nervosa (binge-eating/purging and restricting types), (2) treatment had a relational/family component either as primary or supplementary intervention (e.g., therapeutic alliance, parent-child, partner, spouse, caregiver, support person), (3) the published manuscript focused on intervention and included outcome criteria that specified but was not limited to AN symptomatology, (4) the published manuscript needed to include at least three BPSS domains, (5) the published manuscript was peer-reviewed, and (6) the published manuscript was in English. Studies were excluded if they combined Feeding and Eating Disorder diagnoses in study outcomes (i.e., outcomes were not parsed out from AN). Eight articles were excluded from the review due to the lack of clarity of how family treatment occurred (i.e., authors stated that FBT was “offered” or “optional” without further expansion; Abbate-Daga et al., 2015; Accurso et al., 2015; Bean & Weltzin, 2001; Becker et al., 1981; Eckert et al., 1987; Schmidt et al., 2012; Shapiro et al., 2014; van der Kaap-Deeder et al., 2014).

### **Data Collection Process**

Articles were imported into and managed in Covidence (Veritas Health Innovation, n.d.), an online software for managing systematic reviews. In order to reduce risk of bias, articles were independently reviewed (blindly) by three of the authors. Each person screened approximately two-thirds of the articles. The primary author developed a training protocol and then trained and met with the two other reviewers monthly to resolve conflicts (i.e., differing votes) during the screening phases. In the rare case a conflict could not be resolved, they brought in a third/neutral party. Due to feasibility limitations as a result of the first round of eligibility screening ( $n = 189$ ), the primary author independently performed a second round of screening to focus on the most

current diagnostic conceptualization of AN (APA, 2013; see *PRISMA* Flow Chart in Figure 1). Studies that were published after 2013 and specified *DSM-IV* criteria or ICD-10—including those that excluded amenorrhea criteria—were screened out (e.g., Baucom et al., 2017). Studies published after 2013 that did not specify diagnostic criteria were also excluded (e.g., Murray, 2014). The second round of screening resulted in the exclusion of an additional 169 studies. The final number of studies included in this review was  $n = 20$ . No couple-based interventions were included in the final analysis. Although 20 studies were pulled, only 15 were original research; five others shared the same dataset (e.g., Allan et al., 2018; Dimitropoulos et al., 2019; Dimitropoulos et al., 2018b; Halvorsen & Rø, 2019; Murray et al., 2017).

## **Results**

### **Social Location Outcomes**

Sample data across social location for non-AN family members (parents, caregivers/carers, siblings, partners) was scarce compared to AN family members (children, adolescents, adults; see Table 2). A few studies reported the majority of social location identities for all participants (Dimitropoulos et al., 2018a; 2018b; 2019). A little over half of the studies ( $n = 11$ , 55%) reported race or ethnicity of the AN family members, and only five studies reported race or ethnicity for both non-AN and AN family members (Allan et al., 2018; Dimitropoulos et al., 2018a; 2018b; 2019; Herscovici et al., 2017). Despite the heterogeneity of study location (i.e., Canada, Singapore, Australia, United States, United Kingdom, Norway, Italy, Argentina), the majority of participants were Caucasian/White. None of the studies distinguished between sex and gender and used binary terms (i.e., male, female). Four studies reported parent or caregiver sex (Dimitropoulos et al., 2015; 2018a; 2018b; 2019), and four reported age (Balottin et al., 2018; Dimitropoulos et al., 2018a; 2018b; 2019).

Further demographic analyses revealed that less than half of the studies reported socioeconomic status (i.e., education level or income;  $n = 7$ , 35%). The majority of the families in these studies were higher socioeconomic status (i.e., college educated, higher income). Four studies reported disability status for either a non-AN family member (Dimitropoulos et al., 2018a; 2018b; 2019) or AN family member (Spettigue et al., 2019). Three studies reported religious orientations for all participants (Dimitropoulos et al., 2018a; 2018b; 2019). More than half ( $n = 12$ , 60%) described relational or family structure—with the majority of participants describing intact families. FBTs are being implemented globally; however, the bulk of these studies were conducted with majority samples (i.e., White/Caucasian, female, middle to upper class families). Given all of these diverse demographics, not one study within the review tested group differences by social location.

### **Biopsychosocial-spiritual Outcomes**

There were far more BPS health outcomes than spiritual health outcomes across the studies (see Table 3). All studies reported physical health outcomes by either full remission (i.e., weight restoration;  $\geq 95\%$  estimated body weight or body mass index  $\geq 18.5$  kg/m<sup>2</sup>) or partial remission (i.e.,  $> 85\%$  of estimated body weight). For some studies ( $n = 5$ ), full remission or recovery was measured by physical and psychological outcomes (i.e.,  $> 94$  or  $95\%$  median body mass index plus Eating Disorder Examination Questionnaire [Cooper & Fairburn, 1987] global score within one standard deviation of community norms). Three studies used alternative criteria to measure remission, but consistently included physical and psychological markers (Halvorsen et al., 2018; Iniesta Sepúlveda et al., 2017; Wong et al., 2019). All studies reported increases in weight or body mass index by end of treatment and a few also reported other physical health outcomes (e.g., resumption in menses [Accurso et al., 2018; Herscovici et al., 2017]; physical

activity, no longer met criteria for malnutrition, bradycardia and Postural Orthostatic Tachycardia remitted [Peterson et al., 2016]; increased calorie consumption [Plasencia et al., 2019]). One study only reported physical health outcomes as measured by percent of ideal body weight, hospitalizations, tube-feeding, and medications (Gusella et al., 2017), and found improved physical health outcomes in the adolescents in the FBT compared to the non-FBT group.

The majority of the articles ( $n = 19$ , 95%) reported physical and psychological health outcomes. The psychological health outcomes primarily addressed eating behaviors and attitudes with a few also addressing general psychopathology or mental health concerns such as depression, anxiety, or obsessionality. Even though most found reductions in disordered eating behaviors and attitudes, five studies also reported non-significant psychological changes (e.g., distress tolerance, emotion regulation [Accurso et al., 2018]; state anxiety [Iniesta Sepúlveda et al., 2017]; eating concerns [Plasencia et al., 2019]; drive for thinness, depression and anxiety for AN-binge/purge type, suicidality [Spettigue et al., 2019]; guilt/shame [Halvorsen & Rø, 2019], body dissatisfaction [Halvorsen & Rø, 2019; Spettigue et al., 2019]).

More than half ( $n = 11$ , 55%) reported social outcomes in addition to physical and psychological. The social health outcomes varied but typically addressed improvements in parent (or caregiver) behaviors, expressed emotions, and attitudes/appraisals. Two studies also addressed therapeutic alliance (Accurso et al., 2018; Herscovici et al., 2017). Some studies reported non-significant changes in social health (e.g., parental expressed emotion [Allan et al., 2018; Dimitropoulos et al., 2019; McClelland et al., 2018]; parental self-efficacy, caregiver accommodation [Dimitropoulos et al., 2018b]). Lastly, only one article reported a spiritual health outcome (i.e., coping with unrealistic beliefs regarding food and body size) in addition to

physical, psychological, and social (Halvorsen & Rø, 2019), which was one of the least fulfilled treatment goals according to patients and parents. These studies demonstrate that FBTs have the capacity to address BPSS health indicators, albeit at varying degrees and with varying success.

### **Family-based Treatment Approaches**

All of the studies included dyadic/systemic samples such as parents (mothers and fathers) and adolescents (see Table 2). Only two studies included younger children (7 - 17 years; Halvorsen et al., 2018) or older adults (18 - 57 years; Dimitropoulos et al., 2015). A few studies used the terms caregiver (i.e., parent, sibling, extended family member, partner, friend, or supportive other; Dimitropoulos et al., 2018a; 2018b) or carer (i.e., family members; McClelland et al., 2018). Interestingly, the majority of participants (> 95%) from Dimitropoulos and colleagues' (2018a) study chose to participate in FBT with their family of origin even though they had the option to invite their peers or partners. Only one study included siblings and partners in addition to parents (Dimitropoulos et al., 2015). While novel FBTs are gaining empirical support for improving BPS health outcomes for patients, there are varying outcomes across the different approaches.

The study designs of the FBTs were heterogenous with over half including follow-up assessments ( $n = 11$ , 55%), demonstrating sustainable positive improvement in families over time. Most of the articles ( $n = 16$ , 80%) implemented the Maudsley-FBT approach with some of these studies (six of the 16, 38%) augmenting this approach (e.g., parent emotion coaching, exposure-based, guided self-help, dialectical behavioral skills), highlighting the drawbacks of a manualized and behavior-focused approach to adequately address additional symptomatic behaviors persisting after recovery. Though these approaches provided preliminary support for augmenting Maudsley-FBT, one study was not able to test the efficacy of the parental self-help

approach due to poor follow-up data (Lock et al., 2017). A minority used different family therapy approaches or models (e.g., parental counseling and support [Balottin et al., 2018]; Cognitive-Interpersonal Maintenance Model of AN [Dimitropoulos et al., 2015]; Parents In Charge [Gusella et al., 2017]; Family-based Cognitive-Behavioral Treatment with Exposure Response Prevention [Iniesta Sepúlveda et al., 2017]) and found significant improvements in physical, psychological, and dyadic/family outcomes.

A few studies compared Maudsley-FBT to novel FBTs (i.e., Parent-Focused Treatment [Allan et al., 2018; Le Grange et al., 2016; Murray et al., 2017], Adolescent Focused Therapy [Wong et al., 2019]). These models include separating the parents from the adolescent with AN and the studies reported mixed results. Allan et al. (2018) found that PFT was associated with a decrease in maternal criticism, but not Maudsley-FBT, and Murray et al. (2017) found similar trajectories of weight restoration and reduction in dietary restraint across PFT and Maudsley-FBT. Le Grange et al. (2016) and Wong et al. (2019) found that working with parents separately is potentially effective; however, whereas Wong et al. (2019) found Maudsley-FBT superior over Adolescent Focused Therapy as measured by time to remission at one-year follow-up, Le Grange et al. (2016) found no significant differences in sustained remission at follow-up between Maudsley-FBT and Parent-Focused Treatment. Wong et al. (2019) discussed how these findings differed due to alternative definitions of remission. Despite the adaptive trends in FBTs, not every study reported systemic change for patients and family members, and those that did had mixed relational (i.e., family/dyadic) outcomes. These mixed findings are corroborated by Fisher et al.'s (2019) systematic review which demonstrated insufficient evidence to determine whether one family therapy approach was advantageous over another.

## **Dyadic/Family Systems Outcomes**

More than half of the studies ( $n = 12$ , 60%) reported dyadic/family outcomes. Qualitative differences were observed when comparing the studies without dyadic/family outcomes ( $n = 8$ , 40%) to those with dyadic/family outcomes. The studies without dyadic/family outcomes did not include families at assessment and hinged on physical and psychological outcomes whereas the studies with dyadic/family outcomes included families at assessment and measured dyadic/systemic change in relation to BPS health. Interestingly, there were no qualitative differences between these groups in regards to physical and psychological outcomes. While there was consistent physical health improvement across the studies, two of the studies that reported dyadic/family outcomes also reported nonsignificant psychological outcomes (Accurso et al., 2018; Halvorsen & Rø, 2019) as well as three of the studies without dyadic/family outcomes (Iniesta Sepúlveda et al., 2017; Plasencia et al., 2019; Spettigue et al., 2019).

Among the dyadic/family outcomes, there were interesting similarities and differences that emerged in terms of how family dynamics influenced patient outcomes (i.e., eating disorder behaviors or weight restoration). A few studies found significant improvements in parental self-efficacy (Dimitropoulos et al., 2018b; Lock et al., 2017) and less accommodating behaviors of eating disorder symptoms (e.g., purging, restricting, over-exercising; Dimitropoulos et al., 2018b; McClelland et al., 2018), albeit at different time points. A couple studies found that parental expressed emotion slightly decreased over the course of treatment, but not significantly (Dimitropoulos et al., 2019; McClelland et al., 2018), and Le Grange and colleagues (2016) found that lower paternal expressed emotion was a non-specific predictor of higher remission at follow-up. Allan and colleagues (2018) found no significant effects for paternal expressed emotion, which they attributed to low paternal response rates. Interestingly, Allan et al. (2018)

found that maternal criticism was related to longer illness duration and lower maternal expressed emotion influenced higher rates of patient remission. Others reported that parental changes (i.e., parental expressed emotion, self-efficacy, accommodating behaviors, and perceived family functioning) did not influence patient outcomes despite demonstrating significant improvement in parental self-efficacy, family functioning, and reduction in caregiver accommodating behaviors to eating disorder symptoms over the course of treatment (Dimitropoulos et al., 2018b; 2019).

Dimitropoulos and colleagues (2019) found significant improvement in perceived functioning over time for both patients and parents, and another study discussed the positive result of family restructuring (Herscovici et al., 2017). One study found that adolescents with better outcomes at end of treatment came from families with better intrafamily dynamics (i.e., triadic mother–father–daughter relationships; Balottin et al., 2018). Two studies demonstrated divergence between multiple family perspectives and treatment outcomes (Accurso et al., 2018; Halvorsen & Rø, 2019). Despite parental perceived improvement in eating disorder psychopathology, youth with AN reported less improvement in this area (Accurso et al., 2018). Two studies demonstrated improvements in distress tolerance and reductions in emotion dysregulation among caregivers (Accurso et al., 2018; Peterson et al., 2016), but these findings were not tied to significant improvements for youth (Accurso et al., 2018). Halvorsen and Rø (2019) found divergent perspectives on treatment satisfaction among parents and patients, but concordance among family members on least and most fulfilled treatment goals. These studies demonstrated the mixed BPS health outcomes of patients, divergent and convergent perspectives of family members, and improved dyadic/relational dynamics.

## Discussion

The purpose of this study was to systematically review social location, BPSS, and dyadic/family outcomes in couple and/or family-based intervention studies for AN. Given the evidence that AN is a systemic and relational diagnosis, this study was grounded in FST and the BPSS framework. Couple and/or FBTs address multiple domains of health (e.g., physical, psychological, social) unlike other treatment models, making it a suitable treatment for addressing the BPSS health of individuals with AN within their familial context. The most significant contributions to research from this systematic review include: (1) recognition of the underreporting of social location for non-AN family members, (2) physical and psychological health as elevated over other aspects of health, and (3) the need for a systemic and relational theoretical orientation, which is inconsistently present in FBTs for AN.

First, social location was more commonly missing among non-AN family members compared to AN family members. In fact, 65% of the studies did not report social location for non-AN family members. When reported, AN family members were majority female and White. As mentioned previously, treatment studies skew toward non-Hispanic, White females, which may be attributed to the self-stigma in males (Griffiths et al., 2015), lower rates of treatment seeking for AN among racial/ethnic minoritized groups (Coffino et al., 2019), and clinician bias in diagnosis (Garb, 2021). Although research is limited as it relates to AN prevalence across social location, there is a disproportionate burden of risk for eating disorders/disordered eating among minoritized groups (e.g., transgender individuals, racial and ethnic minorities, Mason et al., 2021).

Moreover, only a few studies reported the majority of social location factors (i.e., sex, race, ethnicity, socioeconomic status, religious orientation, ability status) for all participants,

absent gender identities and sexual orientation. Assessing and analyzing religion and ability status in treatment studies may have important contextual implications for culturally-sensitive treatment approaches. For example, symptomatic behaviors and body image concerns differ across religious and non-religious groups (Wilhelm et al., 2018) and body image concerns may not abate following treatment for individuals with physical limitations (Taleporos & McCabe, 2002). The reporting of sex as opposed to gender identity also has implications for clinician bias and inclusive treatment practices (Garb, 2021). Despite previous researchers dismantling the stereotype that higher socioeconomic status is associated with AN (Gard & Freeman, 1996), the majority of families in these studies were from a middle/high class demographic, which may be due to relevant treatment barriers (e.g., high cost, uninsured/underinsured; Kaye & Bulik, 2021). Lastly, since dyadic/family outcomes were not analyzed by social location, social location implications of FBTs for AN remain largely unknown.

Second, physical and psychological outcomes were consistently reported whereas social and spiritual were underreported or absent. While every article had to include at least three BPSS domains, not all articles measured BPSS health in relation to outcomes. It is not unusual that the majority of these studies reported both physical and psychological outcomes because the *DSM-5* conceptualizes AN as a physical and psychological disorder. Yet, eating disorder providers have found that a myopic focus on weight and body mass index has its limitations (Neumark-Sztainer, 2005) by perpetuating weight stigma and contributing to eating disorders (Ramos Salas, 2015). Recommendations that treatment go beyond symptom management (Kenny et al., 2020) and de-emphasize physical health (Linville et al., 2012) has been voiced by individuals in recovery.

Addressing the BPSS health of the patient within the familial context was not central to FBTs. Nineteen out of 20 studies overlooked the totality of health regardless of the evidence of

BPSS symptomatology. While FBTs are capable of enhancing the BPSS health of patients, the evidence of FBTs influencing spiritual health is inconclusive. The only study (i.e., Halvorsen & Rø, 2019) that measured spiritual health reported an unfavorable outcome. The paucity of evidence regarding spiritual health impact indicates an oversight in FBT studies to address the nuances of spiritual health within a familial context. While it is important to not de-emphasize medical care or physical health because medical stabilization is critical for acute cases and refeeding syndrome is life-threatening (Mehler & Brown, 2015), drawing attention to the pattern of documenting physical health outcomes over other aspects of health is important since this diverges from patients' illness experience (Sibeoni et al., 2017).

Lastly, a systemic and relational theoretical orientation was inconsistently apparent across the studies as evidenced by the underreporting of dyadic/family data despite family inclusion. While family involvement was high from data collection to outcome measures in more than half of the studies, individual-level outcomes were documented more consistently than family-level outcomes. While there were mixed results across the studies in terms of how dyadic/systemic change affected patient outcomes, the improvement in parental behaviors/attitudes highlights the importance of family inclusion.

Across the 20 studies, physical and psychological health data followed a similar trend among the studies with dyadic/family outcomes and those without. Remarkably, every study reported improved physical health, but five of the 20 studies found nonsignificant psychological changes. Interestingly, although Halvorsen and Rø (2019) found that 62% of their sample were weight recovered and 38% were fully recovered at follow-up, patients and their family members retrospectively reported experiencing less fulfillment from FBT in terms of addressing other aspects of health, namely psychological and spiritual (i.e., coping with unrealistic beliefs about

food and body weight/shape). The quarter of studies that observed nonsignificant psychological outcomes may be attributed to the underlying mental health conditions (e.g., obsessive-compulsive, anxiety, depression) that persist following recovery (Kaye et al., 2008).

## **Limitations**

There are a few limitations that need to be addressed. While the most commonly used search engines were utilized, FBTs in contexts known to encounter AN may have been overlooked. If the search criteria were not limited to English only, then more international FBT studies may have emerged. By choosing to lean on the current scientific criteria of AN, additional FBT studies may have been left out. Perhaps a historical review of FBTs for AN could have provided more context of family variables and outcomes over time. Conducting quality methodological assessments of each study using standardized tools may have provided more context to the synthesis of results. Despite these limitations, the findings from this current study draw attention to significant clinical and research implications.

## **Implications**

### **Clinical**

Given the findings from this systematic review, there are six recommendations for clinicians who work with individuals and families with AN:

(1) Aim for family-level interventions by assessing family dynamics and intrafamily functioning. This provides opportunities to improve interpersonal dynamics and achieve positive systemic change. Since AN can disrupt family functioning, it is important that ruptures in family relationships/support systems can be repaired since an individual's sense of connection to self and others significantly influences recovery (Linville et al., 2012).

(2) Assessing social location is an important practice when building rapport with clients and their family members and means more than simply collecting demographic information. A person's social location is part of how they self-identify and experience themselves and treatment may need to be tailored to address diverse experiences.

(3) Separate parents from the adolescent from time to time because this can be helpful in targeting parental maladaptive behaviors and attitudes/appraisals, resulting in an indirect, positive effect on reducing AN symptomatology.

(4) From assessment to planning for discharge, include multiple perspectives of family members throughout treatment and facilitate healthy conflict resolution in terms of illness experiences, treatment expectations, expressed emotions, and supportive practices.

(5) Prepare patients and families for realistic expectations regarding continual mental health support post-treatment (e.g., offer conjoint individual and family therapy to reduce risk of relapse). This is important because risk of relapse is highest within the first year following treatment (Khalsa et al., 2017).

(6) While other therapeutic approaches are helpful, this current study highlighted that family-based models of care produce systemic and relational change. Clinicians who are not well versed in FBTs are encouraged to learn the models and augmented approaches of FBTs for AN, including FST, whereby increasing a clinician's systemic and relational therapeutic lens.

## **Research**

Future FBT studies need to use FST as a guiding framework from design to outcomes as evidenced by the underreporting of dyadic/systemic outcomes. Designing FBT studies that include multiple perspectives is challenging, but can be accomplished with sophisticated analytical methods (Lebow, 2020). Including demographic information for every participant

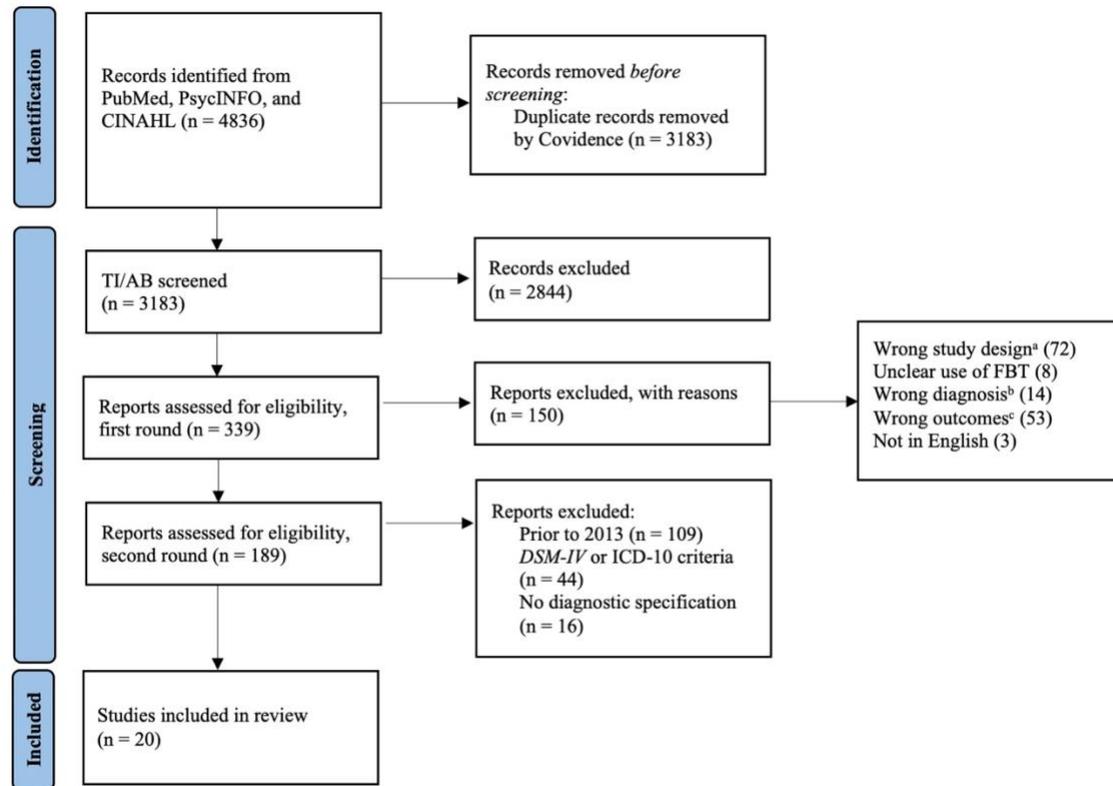
involved in treatment is important for generalizability and informing culturally sensitive treatment approaches. Adapting recruitment efforts to include diverse families that have been historically underrepresented in AN research (e.g., LGBTQ+ and racial/ethnic minoritized families) is also recommended for future studies. Researchers should look beyond the weight criteria in the *DSM* for other BPSS markers to emerge (e.g., sleep disorder symptoms; Christensen & Short, 2021; Malcolm & Phillipou, 2021) in the etiology and maintenance of AN.

### **Conclusion**

This study highlighted a gap in FBTs for AN in terms of addressing social location factors and the whole illness experience of AN. When social location was reported, White females were overrepresented. Adapting recruitment efforts can help improve diverse social locations represented in treatment studies. Overemphasizing physical health in treatment can have implications for recovery, particularly as it relates to societal ideals/standards. Since AN is most lethal of all eating disorders, attending to the *whole person* with AN within their family system can have positive implications for recovery. While treatment is not the cure for AN, it sets the foundation for lasting recovery. As FBTs continue to advance, clinicians across disciplines (e.g., marriage and family therapists, psychiatrists) need to collaboratively work together on meeting the systemic and relational challenges associated with treating AN.

**Figure 1**

A PRISMA flow-chart for eligibility



*Note.* TI = title; AB = abstract; FBT = family-based treatment

<sup>a</sup>These were either not intervention studies or not family-based interventions

<sup>b</sup>These were other restrictive eating disorder diagnoses (e.g., atypical anorexia nervosa)

<sup>c</sup>Outcomes were not parsed out for anorexia nervosa and included outcomes of other diagnoses

**Table 1**

*MeSH Terms and Keywords used in Systematic Review*

Databases*	Anorexia Nervosa	Couple/family therapy
MeSH	“Anorexia Nervosa” [Mesh]	“Couples Therapy” [Mesh] “Family Therapy” [Mesh] Family [Mesh] Caregivers [Mesh] “Interpersonal Relations” [Mesh] “Therapeutic alliance” [Mesh] Religion [Mesh]
Keywords	“Anorexia nervosa” “Anorexia nervosas” Anorexic Anorexics Anorexia Anorectic Anorectics	“couples therapy” “couple therapy” “couple therapies” “couple counseling” “family therapy” “family therapies” “family counseling” “Support system” “support systems” “family members” “family member” Spouse partner “Psychosocial support” Multi-family Multifamily
		Parent Parents Parent-focused Caregiver Caregivers Carer-focused Relational Spiritual Religion Religiosity Religious Faith-based Biopsychosocial Bio-psycho-social Biological AND psychological AND (sociocultural OR socio-cultural OR social)

\*PubMed, PsycINFO, and CINAHL

**Table 2**

*Biopsychosocial-spiritual Outcomes Reported in Family-based Treatments for Anorexia Nervosa*

Author (Year)	Type of study	Intervention(s) used	Physical health outcomes	Psychological health outcomes	Social health outcomes	Spiritual health outcomes
Accurso et al. (2018)	Quasi-experimental study	FBT with DBT or skills enhanced FBT	%mBMI increased (Cohen's <i>d</i> effect size = 1.39). Four participants (36.4%) achieved weight restoration ( $\geq 95\%$ mBMI). Two participants (18.2%) achieved both weight restoration and EDE Global scores within community norms. Participants with amenorrhea ( $n = 5$ ) resumed menses.	Six participants (54.5%) remitted. Caregiver-reported ED psychopathology was higher ( $d = 0.55$ ) than youth report ( $d = 0.08$ ). Youth distress tolerance ( $d = 0.14$ ) and emotion regulation ( $d = 0.10$ ) did not significantly change from BL to EOT.	Patients rated therapeutic alliance as moderate ( $M = 14.1$ , $SD = 13.3$ ) while caregivers rated it highly ( $M = 39.3$ , $SD = 9.5$ ). Caregivers reported increases in distress tolerance ( $d = 0.44$ ) and reductions in emotion dysregulation ( $d = 0.62$ ).	NR
Allan et al. (2018)*	Randomized clinical trial <sup>a</sup>	PFT vs. FBT	NR <sup>b</sup>	NR <sup>b</sup>	High BL maternal criticism was related to longer illness duration ( $SD = 12.38$ , $p = 0.011$ ), and remission was associated with a decrease in maternal EE ( $p = 0.026$ ).	NR
Balotin et al. (2018)	Quasi-experimental study	AFT and parent counseling	BMI increased at EOT	83.3% of adolescents reduced psychopathology (54.17% statistically significant) at EOT.	Better EOT outcome for adolescents with improved interactive abilities and focal attention ( $p < 0.05$ ). Improved patients belonged to families more dysfunctional in dyadic dynamics ( $p < 0.05$ ).	NR
Dimitropoulos et al. (2015)*	Quasi-experimental study	Compared multifamily to single family	BMI increased similarly over the span of treatment for both groups ( $p < .01$ )	Eating psychopathology decreased similarly over the span of treatment for both groups ( $p < .01$ )	Family members experienced decreases in negative caregiving appraisals, criticism, over-involvement, and depressive symptoms similarly for both groups from pre to FU ( $ps < .05$ )	NR

Dimitropoulos et al. (2018a)*	Quasi-experimental study	FBT - open trial for TAY	The %mBMI significantly increased at EOT ( $p = .0001$ ) and FU ( $d = 0.54, p = .0001$ )	Global EDE-Q significantly improved at EOT ( $p = .001$ ) and FU ( $d = 0.34, p = .001$ )	NR	NR
Dimitropoulos et al. (2018b)*	Quasi-experimental study <sup>c</sup>	FBT - TAY	Changes in parental self-efficacy from BL to FU did not significantly predict weight restoration in TAY.	Changes in parental self-efficacy and caregiver accommodation from BL to FU did not significantly predict ED behavior in TAY.	Parental self-efficacy significantly increased from BL to FU ( $p = .002$ ) and caregiver accommodation significantly decreased from BL to EOT ( $p = 0.0001$ )	NR
Dimitropoulos et al. (2019)*	Quasi-experimental study <sup>c</sup>	FBT - TAY	Changes in parental EE and TAYs' and parent's perceived family functioning over time were not significantly associated with weight restoration in TAY.	Changes in parental EE and TAYs' and parents' perceived family functioning over time were not significantly associated with ED behavior in TAY.	Parental EE slightly declined but not significantly. Family functioning significantly improved for both participants and parents over time ( $p = .0001$ ).	NR
Gusella et al. (2017)	Cohort study	PIC vs. NST	Both groups gained weight, but %IBW for youth in PIC group trended upward ( $p = 0.05$ ). NST youth required admission on the psychiatry unit for weight restoration more than PIC youth ( $p = 0.03, d = 0.34$ ). NST youth required tube-feeding while hospitalized more than PIC youth ( $p = 0.006, d = 0.44$ ).	NR	NR	NR

Halvorsen et al. (2018)*	Cohort study	Inpatient FBT	At FU, a total of 65% of the participants had achieved a normal body weight (BMI $\geq 18.5$ ) and were classified as 'weight recovered'.	Of the 33 participants with complete EDE-Q data, 19 (58%) had an EDE-Q global score in the normal range ( $\leq 2.5$ ), as well as no binge eating or purging/other compensatory behavior during the past 3 months.	NR	NR
Halvorsen & Rø (2019)*	Cohort study <sup>d</sup>	Inpatient FBT	Twenty-one (62%) of the participants were weight recovered (i.e., BMI > 18.5)	13 (38%) fully recovered (i.e., normal eating attitudes and behavior defined as an EDE-Q global score < 2.5, no binge eating/purging during the past three months, and BMI > 18.5)	Parents reported a high level of satisfaction with all central aspects of treatment ( $p < 0.001$ )	Learning to cope with unrealistic beliefs was one of the least fulfilled goals by all family members ( $d = 0.7, p = 0.008$ ).
Herscovici et al. (2017)*	Randomized controlled trial	Two groups (1 FBT and 1 FBT-FMI)	11 (48%) patients reached normal weight. Average weight recovery for all patients increased at EOT by FU ( $ps < 0.005$ ). Resumption of menses for half of female patients by EOT.	Eating psychopathology reduced ( $ps < 0.005$ ). Significant treatment effects for ED and general psychopathology, $d = 2.73$ and $d = 10.61$ , respectively.	Family structure was rearranged, parental engagement in meal support, and therapeutic alliance strengthened.	NR
Iniesta Sepúlveda et al. (2017)	Quasi-experimental study	Family-based intensive CBT utilizing ERP	Weight and BMI increased. 100% of participants reached a BMI in normal range.	Symptom severity improved ( $M = -1.33 \pm 1.02$ ); body checking decreased ( $M = -16.16 \pm 14.82$ ); quality of life increased ( $M = 11.83 \pm 10.74$ ); depressive symptoms improved ( $M = -6.87 \pm 3.60$ ); trait anxiety decreased ( $M = -10.00 \pm 10.22$ ). Non-significant decrease for state anxiety ( $M = -8.40 \pm 14.06$ ).	NR	NR
Le Grange et al. (2016)*	Randomized clinical trial	PFT vs. FBT	Remission rates at EOT were significantly higher for PFT than FBT ( $p = .016$ ).	ED psychopathology and ED-related obsessions and compulsions moderated outcome at 6- and 12-month FU.	BL EE (father) ( $p = .024$ ) emerged as a nonspecific predictor of remission at 6-month FU. Lower paternal EE showed higher remission at FU.	NR

Lock et al. (2017)*	Quasi-experimental study	Parental GSH-FBT	BMI increased ( $p < .001$ ). At EOT, 68% of adolescents were remitted, 26% were partially remitted but not fully weight restored, and one patient was not weight restored. At FU, 78% were weight remitted and 22% were partially remitted.	At EOT, full recovery was 45.5%, partial recovery was 45.5%, and one participant was unrecovered at EOT. Out of the 8 participants for whom FU data included both weight and EDE-Q scores, 37.5% were recovered and the remainder (62.5%) were partially recovered.	Parental self-efficacy improved from BL to EOT ( $p < .001$ )	NR
McClelland et al. (2018)	Cohort study	FREED + FBT	FREED AN patients (nearly 60%) returned to a normal BMI ( $>18.5 \text{ kg/m}^2$ ) at 12 months. Marginal BMI was lower in the 28 audit-AN patients than FREED AN patients, but not significantly ( $p = .100$ ).	For FREED AN, by T4, 70% of patients were below clinical cut-off (i.e., $< 2.8$ ) of EDE-Q score. General psychopathology ( $p = .001$ ), secondary psychosocial impairment ( $p = .001$ ), and EE ( $p = .102$ ) improved from 0-12 months.	Improved general psychopathology ( $p = .001$ ), EE ( $p = .503$ ), and less accommodation of ED symptoms ( $p = .001$ ) in carers of patients in the FREED service.	NR
Murray et al. (2017)	Randomized clinical trial <sup>a</sup>	PFT vs. FBT	Comparable symptom trajectories of weight normalization across FBT and PFT. Weight increased over the course of treatment ( $p < .001$ ).	Comparable symptom trajectories of dietary restraint and positive and negative affect across FBT and PFT. Increases in positive affect ( $p < .001$ ) and decreases in dietary restraint ( $p < .001$ ) and negative affect ( $p < .001$ ).	NR	NR
Peterson et al. (2016)	Case study	FBT w/ Parent Emotion Coaching	No longer met criteria for malnutrition (zBMI score = $-0.5$ ). Gained weight (40 <sup>th</sup> percentile), resumed physical activity, and bradycardia and POTS remitted.	No fear of weight gain or distorted body image, mood improved, and parent-reported reduced anxiety.	Parental increase in distress tolerance, increased conflict resolution skills, and emotion regulation. At FU, parent-reported improved adolescent engagement with family.	NR

Plasencia et al. (2019)	Case report	ABIE prior to FBT	Weight increased to 106 pounds and following 20 sessions of FBT subsequent to ABIE, increased to 115 pounds. Patient consumed more calories during an open meal presented to her prior to and following ABIE.	Global EDE-Q and most subscales demonstrated reliable change ( $p < .05$ ). Eating concern failed to reach this cutoff. Global disgust increased from pre (77) to post (80).	NR	NR
Spettigue et al. (2019)	Cohort study	Inpatient FBT	For both AN-R and AN-BP, there were significant increases in BMI ( $p < .001$ )	ED symptoms significantly decreased in AN-R cohort ( $p < .001$ ), but not AN-BP ( $p = .009$ ). Nonsignificant reduction in drive for thinness for AN-R ( $d = 0.31$ ) and AN-BP ( $d = 0.96$ ). Nonsignificant improvement in body dissatisfaction for AN-BP ( $p = .098$ ) and AN-R ( $p = .086$ ). Depression and anxiety decreased for AN-R ( $p < .001$ ), but not for AN-BP ( $p = .027$ ). 34.55% patients endorsed suicidality at EOT.	NR	NR
Wong et al. (2019)*	Cohort study	FBT v. AFT	Longer time to remission for non-FBT patients compared with FBT patients ( $p < 0.001$ ). FBT patients achieved higher rates of remission at both 1 (69%) and 2 years (90%) than non-FBT group (30% and 57% respectively).	NR <sup>e</sup>	NR	NR

*Note.* FBT = Family-Based Treatment; DBT = Dialectical Behavior Therapy; %mBMI = percent of median body mass index; ED = eating disorder; M = mean; SD = standard deviation; BL = baseline; EOT = end of treatment; PFT = Parent-Focused Treatment; NR = not reported; EE = expressed emotion; AFT = Adolescent Focused Therapy; FU = follow-up; TAY = transition age youth; EDE-Q = Eating Disorders Examination Questionnaire; PIC = Parents In Charge; NST = Non-Specific Therapy; %IBW = percent of ideal body weight; FMI = Family Meal Intervention; CBT = Cognitive-Behavioral Therapy; ERP = Exposure Response Prevention; GSH = Guided Self-Help; FREED = First Episode and Rapid Early Intervention for Eating Disorders; POTS = Postural Orthostatic Tachycardia; ABIE = Acceptance-Based Interoceptive Exposure; AN-R = anorexia nervosa restricting type; AN-BP = anorexia nervosa binge/purge type

<sup>a</sup>Same sample data from Le Grange et al., 2016

<sup>b</sup>Although the %mBMI and EDE-Q were not specifically reported, they were used in analyses as markers of remission.

<sup>c</sup>Same sample data from Dimitropoulos et al., 2018a

<sup>d</sup>Same sample data from Halvorsen et al., 2018

<sup>e</sup>Although remission included *DSM-5* criteria, psychological outcomes were not specified.

\*Included follow-up assessment

**Table 3***Participant Demographics Reported in Family-based Treatments for Anorexia Nervosa*

Author (Year)	Family members with AN					Family members without AN		
	Participants <i>N</i>	Age	Sex/Gender	Race/ Ethnicity	Country	Age	Sex/Gender	Race/ Ethnicity
Accurso et al. (2018)	11 youth and parents	11 - 18 years (M = 15.47 years)	Female (100%)	Non-Hispanic Caucasian (100%)	US	NR	NR	NR
Allan et al. (2018) <sup>a</sup>	102 adolescents and parents	12 - 18 years	Female (89%)	Australian-born	NR	NR	NR	Australian-born
Balottin et al. (2018)	24 families (72 adolescents)	13 - 18 years	Female (n = 72)	NR	Italy	Parents: Father: (36 - 64 years), Mother: (36 - 57 years)	NR	NR
Dimitropoulos et al. (2015)	37 adults and 45 family members (mothers, fathers, partners, siblings)	18 - 57 years	Female (n = 37)	NR	Canada	NR	Male (n = 38, 52.78%)	NR
Dimitropoulos et al. (2018a) <sup>ab</sup>	26 older adolescents and young adults and 50 caregivers	16 - 22 years	Female (n = 25) Male (n = 1)	Caucasian (61.5%), Bi-racial (7.7%), Indian (3.8%), Hispanic (11.5%), Asian (11.5%), Persian (3.8%)	Canada	M = 46.00	Female (n = 30) Male (n = 20)	Caucasian (72%), Non-Caucasian (28%)
Dimitropoulos et al. (2018b) <sup>ab</sup>	26 older adolescents and young adults and 23 mothers and 16 fathers	16 - 22 years	Female (96.2%)	Caucasian (61.5%)	Canada	40 - 71 years	Female (n = 23) Male (n = 16)	Caucasian (66.7%)

Dimitropoulos et al. (2019) <sup>ab</sup>	26 older adolescents and young adults and 42 parents	16 - 22 years	Female (n = 25) Male (n = 1)	Caucasian (65.4%)	Canada	M = 50.9	Female (n = 25, 66.7%), Male (n = 17, 33.3%);	Caucasian (65.9%), Non-Caucasian (34.2%)
Gusella et al. (2017)	46 youth and parents	9 - 15 years	Female (n = 43) Male (n = 3)	NR	Canada	NR	NR	NR
Halvorsen et al. (2018)	37 adolescents and young adults, and parents	BL Age (12.4 - 19.5 years); FU Age (15.8 - 25.3 years)	Female (n = 33) Male (n = 4)	NR	Norway	NR	NR	NR
Halvorsen & Rø (2019) <sup>a</sup>	34 former patients and 60 parents	BL Age (M = 15.8 ± 1.8 years); FU Age (M = 20.4 ± 2.7 years)	NR	NR	Norway	NR	NR	NR
Herscovici et al. (2017)	23 families (23 adolescents and parents)	12 - 20 years	Female (n = 22) Male (n = 1)	White	Argentina	NR	NR	White
Iniesta Sepúlveda et al. (2017)	8 adolescents and parents	11 - 15 years	Female (n = 8)	Caucasian	US	NR	NR	NR
Le Grange et al. (2016) <sup>a</sup>	106 adolescents and parents	12 - 18 years	Female (n = 93, 87.7%)	Australian-born	Australia	NR	NR	NR
Lock et al. (2017) <sup>a</sup>	19 adolescents and parents	11 - 18 years (M = 15.0 years)	Female (90%)	White (95%)	US	NR	NR	NR
McClelland et al. (2018)	56 young adults and 19 carers	18 - 25 years (M = 19.3 years)	Female (n = 54, 96%)	NR	UK	NR	NR	NR
Murray et al. (2017)	107 adolescents and parents	12 - 18 years	Female (87.7%)	Australian-born	Australia	NR	NR	NR
Peterson et al. (2016)	1 family (1 adolescent, 2 parents)	13 - 14 years	Male	NR	US	NR	NR	NR

Plasencia et al. (2019)	1 family (1 adolescent, 2 parents)	16 years	Female	NR	US	NR	NR	NR
Spettigue et al. (2019) <sup>ac</sup>	153 adolescents and 133 parents	13 – 18 years	Female (100%)	NR	Canada	NR	NR	NR
Wong et al. (2019)	119 adolescents and parents	M = 14.6 years	Female (n = 114)	Chinese (n = 94), Indian (n = 13), Malay (n = 3), Other (n = 9)	Singapore	NR	NR	NR

*Note.* M = mean; US = United States; NR = not reported; BL = baseline; FU = follow-up; UK = United Kingdom

<sup>a</sup>These studies also reported socioeconomic status.

<sup>b</sup>These studies also reported religious orientation and disability status.

<sup>c</sup>This study also reported learning disability status.

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## CHAPTER 4: A MIXED METHODS APPROACH FOR UNDERSTANDING THE LIVED EXPERIENCE OF DIET CULTURE IN RECOVERY

While Western culture in the 21<sup>st</sup> century seems to be moving toward body positivity (i.e., promotion and acceptance of all bodies), the pervasive promotion of an “ideal” body size or shape continues in North American society in the guise of “health and wellness” (Harrison, 2019). Within the past decade, making healthier lifestyle changes—as opposed to sticking to a diet—has become an increasingly more popular trend among U.S. consumers (The NPD Group, 2020). Nonetheless, over the last few years, 49.7% of young adults (aged 20-39 years; Martin et al., 2018) and 37.6% of adolescents (aged 16-19 years; McDow et al., 2019) in the U.S. reported attempting to lose weight. Among those attempting to lose weight, 25% report adhering to a diet plan, 16% report following their “own diet” (i.e., closely monitoring food intake), and nearly 10% follow the ketogenic diet (originally used in the 1920s to treat pediatric epilepsy; Wheless, 2008) and intermittent fasting (i.e., cycle of fasting and eating; The NPD Group, 2020). Since 2018, the weight loss market in the U.S. has seen a 4% revenue increase to \$72 billion (LaRosa, 2019), fueled by a societal focus on weight and body size. This market is far-reaching. It reaches not only food and beverage, sports and fitness, and cosmetics but also the healthcare industry. In fact, bariatric surgeries have been increasing 5% per year while prescription obesity drugs are a \$655 million market.

Due to the rising rates of obesity in the U.S. (Hales et al., 2020), health professionals have recommended individuals with a higher body mass index ( $\geq 25$ ) to lose weight in order to decrease risk of chronic health conditions (National Heart, Lung, and Blood Institute, n.d.). However, this myopic focus on body mass index as a measurement of physical health has its limitations (Nuttall, 2015). Public health experts have called for reconciling public health

messages about obesity prevention and eating disorders (Neumark-Sztainer, 2005, 2009; Schwartz & Henderson, 2009) due to inadvertent outcomes from the public health “war on obesity” such as stigma, disordered eating, anorexia, dieting, and body dissatisfaction (Ramos Salas, 2015). Health at Every Size is a growing movement to address weight stigma and bias for individuals living with obesity (Penney & Kirk, 2015). The Health at Every Size movement is attempting to shift the societal focus from weight to health, emphasize intuitive eating, body acceptance, and physical activity for movement and health rather than shape and weight. This movement also attempts to fight against diet culture—a system of beliefs and values that elevates physical health by attaching morality to food choices, eating behaviors, and physical appearance (Morris, 2020).

Although dieting has become a less favorable term among U.S. consumers, one does not have to be following a diet to be a part of diet culture—it is endemic to American society (Harrison, 2018, 2019; Trollope-Kumar, 2020). Diet culture has played a significant role in forcing the dieting industry to move toward selling “health and wellness” (Chen, 2016). As of 2018, the wellness industry was worth \$4.2 trillion with increasing projected growth (Global Wellness Institute, 2018). Diet culture perpetuates the societal elevation of physical health as the epitome of what it means to be healthy and manifests in many ways such as the “Eat Clean” movement (“good” versus “bad” food), fad diets, nutrition programs, diet products, weight-loss businesses, and physical fitness training programs (Trollope-Kumar, 2020). Diet culture spreads myths about nutrition and physical activity (National Institute of Diabetes and Digestive and Kidney Diseases, 2017) by pathologizing larger body sizes, encouraging external rules of what, when, and how much to eat, and suggesting body movement as punishment for or prevention of becoming fat (Chastain, 2019). For this reason, diet culture has been related to a system of

oppression (Harrison, 2018)—by promoting weight loss in order to achieve a higher status. Individuals that benefit from this system tend to have thin bodies (thin privilege) whereas individuals with larger bodies are pathologized (fat shamed). Undoubtedly, diet culture is an insidious and oppressive system, which some believe needs to be dismantled.

Though understudied, the link between disordered eating (i.e., compulsive or restrictive eating behaviors), eating disorders (e.g., binge eating disorder, bulimia nervosa, anorexia nervosa [AN]), and diet culture is significant (Schiavo-Campo, 2021). AN—the focus of this current study—is defined as restriction of energy intake leading to significantly low weight, intense fear of gaining weight or becoming ‘fat’, and body weight or shape disturbance (American Psychiatric Association [APA], 2013). As a life-threatening biopsychosocial (Culbert et al., 2015) illness, there are also significant spiritual health implications (i.e., belief systems in relation to self, food, eating, and body; Stockford et al., 2019). A more recent study found that internalization of diet culture (i.e., degree of accepting broader cultural beliefs and standards of eating practices and physical appearance as one’s own personal beliefs and standards) was positively related to disordered eating behaviors, thin idealization, weight bias internalization, fatphobia, and body shame and surveillance, while negatively related to intuitive eating, body satisfaction, flexible views of beauty, self-compassion, and self-esteem (Morris, 2020). As a system of oppression, diet culture permeates a variety of social contexts (e.g., home, school or workplace, healthcare, social media).

One of these contexts (i.e., social media or the Internet) easily disseminates and spreads diet culture beliefs and values (e.g., thin ideal, fatphobia, rigid rules around eating). For years, social media has been more than social networking and connecting with friends and family, it has functioned as a source of health information (Perrin, 2015). Unfortunately, not all health

information from social media is health-promoting. Some online content is health-compromising as it promotes disordered eating/eating disorders (e.g., pro-anorexia websites, thinspiration; Christodoulou, 2012; Saul & Rodgers, 2018). Some pro-eating disorder content goes as far as to perpetuate the belief that AN is a life choice and not a mental illness, and seek to recruit other members in their community (Rodgers et al., 2012).

Fortunately, there are widespread efforts working to challenge harmful online content relevant to disordered eating and eating disorders. Researchers and advocates have also been attempting to sound the alarm regarding diet culture and the adverse health outcomes. While anti-diet culture advocates are not anti-health or anti-medical nutrition therapy (Harrison, 2018), they work to dismantle the myths about health perpetuated by diet culture. Not only are there proclaimed anti-diet dietitians on social media (James, 2020), there are professional organizations (i.e., AN and Associated Disorders) and social media platforms (e.g., Pinterest and Tumblr) that have worked to ban harmful online content relevant to eating disorders (Rodgers et al., 2016). Online support groups (e.g., pro-recovery groups) also provide a safe space for individuals in recovery from AN seeking guidance and information (Eichhorn, 2008).

Although individuals in recovery from AN may believe they have side stepped this health condition, they are not immune to developing disordered eating symptoms or other specified feeding or eating disorders (e.g., orthorexia nervosa). Although not recognized as a *DSM-5* diagnosis (APA, 2013), proposed diagnostic criteria for orthorexia nervosa is (1) an obsession with healthy eating, (2) emotional distress/anxiety when self-imposed nutritional rules are not followed, (3) psychosocial impairments, and (4) malnutrition and/or weight loss (Cena et al., 2019). Not only do these health conditions share similar symptomatology and common traits (e.g., anxiety, obsessive-compulsive, and perfectionism; Scarff, 2017)—the obsessionality and

rigidity around food, eating, and body weight/shape concerns are also associated with internalizing diet culture.

Due to the paucity of research around diet culture, its role in recovery for individuals who have suffered from AN has yet to be determined. As such, this is a gap in relapse prevention that needs to be addressed. While barriers to recovery continue to exist (e.g., societal ideals/standards, the anorexic voice/dual identity, maladaptive beliefs regarding eating and appearance; Smethurst & Kuss, 2018; Smith et al., 2016), a recent cohort study found that only a minority of patients with AN (30%) fully recovered nine years after diagnosis (Franko et al., 2018). Not only are these individuals at risk for adopting orthorexic beliefs and behaviors (e.g., removing “unhealthy or bad” food groups from diet, intermittent fasting, excessive exercise), but also relapsing. Maladaptive beliefs can quickly turn into disordered eating behaviors, which can inevitably lead to relapse. What’s more, although diet culture permeates social contexts, the experience of diet culture within relationships (i.e., family functioning, interpersonal dynamics) also remains unknown. For these reasons, it is important to study the experience of diet culture for individuals in recovery from AN.

As mentioned earlier, there is growing evidence that diet culture—as a sociocultural system—may have physical, psychological, and spiritual health implications. However, no study has examined the experience of diet culture, much less the biopsychosocial-spiritual (BPSS) health experience, for individuals in recovery from AN. Therefore, the purpose of this current study is to give context and gain a more nuanced understanding of the lived experience of diet culture for individuals in recovery from AN. The primary research question for the current study is: “How do individuals in recovery from AN experience diet culture?” My secondary research question is theory-driven and asks: “What are the BPSS experiences of diet culture for

individuals in recovery from AN?” The following sections will describe the theoretical orientation grounding the current study and the methodology.

### **Theoretical Orientation**

The BPSS framework (Engel, 1977, 1980; Wright et al., 1996) and social cognitive theory (Bandura, 1986, 1999) grounded this study. Built upon general system theory (von Bertalanffy, 1968), the BPSS framework explains how multiple systems (e.g., community, family, two-person, person) interact to influence health choices and behaviors. This framework also includes the role of spirituality (i.e., belief systems; Wright et al., 1996) as it relates to health and coping with illness. Stated differently, an individual’s health includes multiple aspects (i.e., biological/physical, psychological, social, spiritual). This framework helps to conceptualize two important points: (1) AN is a BPSS illness and (2) systems outside the individual also influence personal health choices and behaviors.

Social cognitive theory is based on reciprocal determinism (i.e., triadic interplay of person, environment, and behaviors), which refers to the interaction between personal (e.g., self-efficacy, knowledge, outcome expectations) and environmental (e.g., cultural beliefs/norms, social support, observational learning) factors and their mutual influence on health (Bandura, 1986, 1999). Said differently, this theory explains how health behaviors (i.e., health-enhancing or health-compromising) are influenced by how a person interacts with their environment.

Integrated together, the BPSS framework (Engel, 1977, 1980; Wright et al., 1996) and social cognitive theory (Bandura, 1986, 1999) explain how individuals in recovery from AN may be at risk for internalizing diet culture beliefs and values by observing behaviors related to food choices, eating patterns, and body movement or physical activity within their environment (e.g., home, school/work, social media). Since a person in recovery is embedded within an

environmental and sociocultural context, larger systemic influences are likely to overlay their BPSS health experience in recovery. An illustration integrating the research-informed concepts from these theories is depicted in Figure 1 and was applied and tested in Chapter 5.

## **Methods**

### **Study Design and Approach**

This current study used an embedded mixed methods design with a dominant qualitative (i.e., phenomenological) approach (Creswell, 2015). Given the limited research related to diet culture (Davidson, 2020; Jovanovski, & Jaeger, 2022; Morris, 2020), a mixed methods approach was the best design to answer the research questions. Mixed methods approaches are useful in filling the gaps of single study designs and providing more context and nuance to a subject (Creswell, 2015; Creswell & Poth, 2018). An embedded mixed methods approach involved using both a survey and one-on-one interviews. The survey was online and took place prior to the interviews. The survey results were used to inform the qualitative analysis. Due to the absence of research related to the experience of diet culture, a pilot study was conducted which was approved by East Carolina University's Institutional Review Board (IRB #21-000574; see Appendix A). The pilot study was a one-on-one interview with an individual in recovery from AN and their answers helped shape the theoretical framework, research questions, and interview guide for the current study.

### **Study Population and Recruitment**

Individuals were included if they were 18 years of age or older and did not have an active eating disorder. Inclusion criteria also consisted of no longer meeting *DSM-5* criteria (APA, 2013), which was collected at the beginning of the survey. This was self-reported and defined by: (1) most of the time they are consuming enough to maintain nutritional balance or believe

they are within their healthy weight range, (2) most of the time they do not feel intense fear of gaining weight or compensate to avoid their body from becoming larger (e.g., skip meals, over-exercise), and (3) most of the time they do not feel disturbed or in distress about body weight or shape. Individuals also rated their sense of separation from AN and interpersonal conflict caused by food choices, eating behaviors, or physical appearance. Individuals who were unable to affirm the recovery criteria at beginning of survey were excluded from participating in the survey and interview (later amended, see Methods in Chapter 5).

Eligible participants were identified through purposive and convenience sampling (i.e., personal relationships). Individuals in recovery from AN are a hard-to-reach population, and therefore, recruitment involved snowball sampling (Heckathorn, 2011). A purposive homogeneous snowball sample has been previously recommended for phenomenological research (Smith et al., 2009). Qualitative research is concerned with quality, not quantity, and small sample sizes for phenomenological research have been previously recommended (e.g., three to six participants; Smith et al., 2009). Other qualitative researchers (outside of IPA) have contended that point of saturation (i.e., no new information or themes observed in the data) can be achieved in the first twelve interviews and as early as six (Guest et al., 2006). The principal investigator aimed to recruit anywhere from six to 12 participants.

Recruitment included contacting individuals with whom the principal investigator had a pre-existing relationship. These were individuals in recovery from AN and she also requested their voluntary assistance for referrals of other qualified participants (Smith et al., 2009). Participants were recruited from across the United States either via a recruitment e-mail or flyer posted on social media platforms (see Appendices C & D for recruitment materials). The principal investigator provided the survey link to the recruiters to share with eligible individuals

and corresponded with eligible individuals who contacted the principal investigator directly via the flyer posted on social media.

After recruitment, an online survey through Qualtrics (<https://www.qualtrics.com>) was distributed, which contained the consent form (see Appendix E for informed consent), screening for eligibility criteria, and collection of demographics, recovery experiences, and survey items related to diet culture and family functioning. After the interviews were completed, participants were compensated with a \$20 Amazon gift card for their time and valuable contribution.

### ***Measures***

The measurements described below can be traced to the theoretical frameworks grounding this study. Since AN is a systemic illness, it is important to measure other markers that may be impacted as a result of the illness (e.g., belief systems, relationships). As such, internalization of diet culture measures the degree to which someone has assimilated external values and beliefs as one's own and family functioning measures the perception of family functioning according to the participant. It is assumed that the experience of recovery overlays every aspect of health (i.e., BPSS), and therefore, the experience of diet culture is likely to overlay health experiences. This assumption is supported by social cognitive theory, which describes how individuals' behaviors are influenced by their own personal factors (e.g., knowledge/beliefs), cultural norms/values (e.g., diet culture), and social environment (e.g., family, social media). Interview questions were aimed at capturing the essence of diet culture by exploring how it is experienced across all aspects of health.

In keeping with phenomenological methods (Smith et al., 2009), some items in the interview guide (see Appendix F) were open-ended and not theory-led (e.g., "What does this definition [of diet culture] mean to you?") and some were more directed and theory-driven (e.g.,

“What roles does education or learning play in your experience of diet culture?”). The interview guide also contained follow-up questions from the survey in order to provide more systemic context (e.g., interactional dynamics, circular questioning) and nuanced experiential meaning (i.e., phenomenological) to the standardized instruments. The quantitative and qualitative measures combined helped inform the role diet culture plays in the lives of individuals in recovery.

**Demographics.** A survey was distributed to collect social location information including age, race, ethnicity, gender identity, married/partnered, employment/occupational role, ability status, and other relevant data such as age when first diagnosed with AN, time (months or years) in recovery, if or when they relapsed, and other items related to their experience of diet culture in recovery (see Appendix B for survey).

**Internalization of Diet Culture.** Internalization of diet culture was measured with the Internalized Diet Culture Scale (IDCS; Morris, 2020). The scale contains 20 items and will be measured on a 5-point Likert scale (from 1 for strongly disagree to 5 for strongly agree). Higher scores indicate higher degree of internalization of diet culture and lower scores indicate lower degree of internalization of diet culture. The IDCS includes four subdimensions. The categories include (1) Judgment of Self (i.e., own moral character based on diet, eating behaviors, or physical appearance resulting in feelings of guilt or shame), (2) Judgment of Others (i.e., others’ moral character or worthiness based on diet, eating behaviors, or physical appearance), (3) Overvaluing Physical Appearance (i.e., overemphasizing the importance of body size as it relates to health and wellness), and (4) Strictness (i.e., setting inflexible rules regarding one’s own food consumption; Morris, 2020). The scale has been validated with a single sample and demonstrated strong internal consistency (Cronbach’s alpha = 0.964), but further testing is needed for further

evidence of its psychometric generalizability (Morris, 2020). Sample items include: “I feel like a lesser person when I see people who appear more physically fit than me” and “I feel like a lesser person when I eat unhealthy food”.

**Family Functioning.** Family functioning was measured with the shortened version of the General Functioning Subscale (12-items) of the Family Assessment Device (GF12-FAD; Boterhoven de Haan et al., 2015). The scale has been validated and is a reliable tool for measuring overall family functioning. The correlation between GF12-FAD subscale and the six positive items from the General Functioning subscale (GF6+) was high, 0.909 (95% CI: 0.90-0.9; Boterhoven de Haan et al., 2015). A confirmatory factor model confirmed the goodness of fit between items in the GF12-FAD and GF6+ subscale (SRMR < 0.03; RMSEA < 0.05; Boterhoven de Haan et al., 2015). Six items of the GF12-FAD measure healthy family functioning and six items reflect unhealthy functioning. Scoring is on a 5-point Likert scale (from 1 for strongly agree to 5 for strongly disagree) with the scale for the negatively worded items reversed. Higher scores indicate worse family functioning and lower scores indicate better family functioning. Sample items from the GF12-FAD include: “In times of crisis we can turn to each other for support”, “Individuals are accepted for what they are”, and “We avoid discussing our fears and concerns”.

### **Data Collection**

Data was collected through a survey and semi-structured, in-depth one-on-one interviews (see Appendix F for interview guide). The survey was 15-30 minutes to complete and was available for individuals to complete on their own time. Individuals provided their preferred method of contact at completion of the survey to schedule an interview. The principal investigator contacted the individuals to schedule the one-on-one interview, which took place via

Zoom (<https://www.zoom.us/>). The interviews were video/audio recorded with personal identifiers removed from the transcripts for storage and ranged from 45-90 minutes. Surveys were anonymously linked to the interviews. The topics that were covered in the interview guide included the role of diet culture in recovery, whole health experiences of diet culture, and what it means for them to be healthy. Transcripts were imported into a qualitative data analysis software, NVivo (<https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>) for data management and analysis. Following the interview, individuals received a list of resources via email in case additional support was warranted (see Appendix G for list of resources). Since a version of this current study (i.e., pilot study) was already approved (IRB 21-000574), minimal amendments were submitted to update the existing application.

### **Analysis Approach**

Quantitative analysis took place in SPSS Version 28 and included frequency and descriptive statistics (e.g., means, standard deviations) to enumerate survey items and inform the qualitative data. Qualitative analysis took place in NVivo and Microsoft Excel. The qualitative analysis approach was informed by interpretative phenomenological analysis (IPA; Smith et al., 2009). IPA has origins in the field of health psychology as a method to understand experiential and qualitative health experiences (Smith et al., 2009) and is becoming an increasingly more popular approach across other fields of study in order to understand individual experiences related to the human condition (Smith et al., 2009). Key theoretical underpinnings of IPA include phenomenology (i.e., study of experience), hermeneutics (i.e., theory of interpretation), and idiography (i.e., study of the individual; Smith et al., 2009). This approach aims to give voice and meaning to the subjective and inner experience of individuals (Larkin et al., 2006; Smith & Shinebourne, 2012). This approach was used for this study because it is important to gain a better

understanding of the experience of diet culture for individuals in recovery from AN given the absence of research around this phenomenon.

Since IPA research aims to be more inductive than deductive, the primary research question was epistemological and process-oriented in order to avoid “*a priori* theoretical constructs upon the phenomena” (Smith et al., 2009, p. 47). However, the secondary research question was theory-driven and answered during the interpretative stage (Smith et al., 2009). This recommendation by Smith et al. (2009) was followed in this study as evidenced by the primary and secondary research questions.

IPA is an iterative process, including various strategies. The IPA strategies followed in this study consisted of finding patterns in the data (i.e., similarities and differences), collaborating with research team to ensure coherence and plausibility of interpretations, dialoging with committee members (i.e., research team), coded data, and psychological knowledge of participants’ claims and concerns, developing an interpretative narrative, and ongoing reflection of the participants’ language, choice of words, and interpretations (Smith et al., 2009). Developing codes was an important process to inform themes, and mixed coding techniques were employed (e.g., descriptive, In Vivo, process codes; Saldaña, 2016; Smith et al., 2009).

Also inherent to qualitative inquiry is the reflexivity (or personal bracketing) of the researcher (Creswell & Poth, 2018; van Manen, 2014). This takes into account the researcher as a key instrument in data collection (i.e., dialoging with interviewee; Smith et al., 2009) and analysis (i.e., “reflective engagement”; Smith et al., 2009). Practicing reflexivity for the principal investigator entailed bracketing herself as a medical family therapist who works with individuals with disordered eating/eating disorders, but no history of being diagnosed with AN or being in

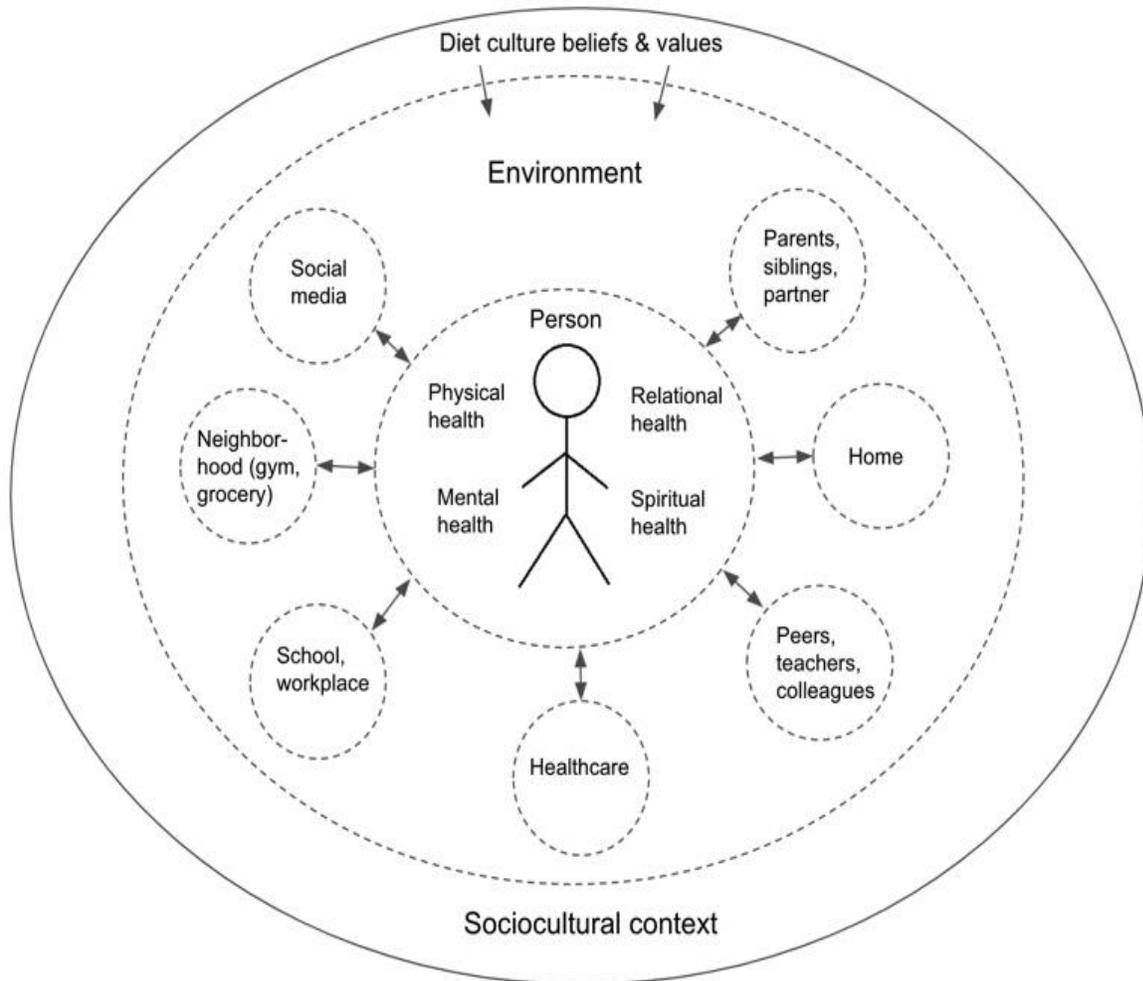
recovery from AN, only close relationships with others who have been diagnosed and are in active recovery.

### **Conclusion**

Diet culture is a system of oppression that elevates and moralizes food choices, eating behaviors, and physical appearance standards. Diet culture spreads through social media and other social contexts/environments (e.g., home, school/work). Although the relationship between ‘diet culture’ and the development of AN is less known, it can be implied that diet culture has negatively contributed to this life-threatening health condition. Unfortunately, individuals in recovery from AN continue to face health challenges, but the experience of diet culture for these individuals is unknown. Given the multifactorial nature of AN and diet culture as a system of oppression that can be observed in social contexts, this current study was grounded in the BPSS framework (Engel, 1977, 1980; Wright et al., 1996) and social cognitive theory (Bandura, 1986, 1999). A mixed methods study design with a phenomenological analysis approach was well suited to answer the research questions and provide more context and meaning to the experience of diet culture. Not only is it important to understand the lived experience of diet culture to fill a gap in recovery research, but also improve relapse prevention.

**Figure 1**

*A Theoretical Model of Social Cognitive Theory and the Biopsychosocial-spiritual Framework*



*Note.* This illustration demonstrates concepts central to social cognitive theory and the biopsychosocial-spiritual framework. The dotted lines represent the permeability between systems in which a person in recovery exists (i.e., sociocultural context, environment) and the process by which diet culture beliefs and values are passed through the environment and experienced on a personal level. Bidirectional arrows represent the reciprocal influences on the person and their environment as it relates to their personal health choices and behaviors.

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## CHAPTER 5: THE EXPERIENCE OF DIET CULTURE FOR INDIVIDUALS IN RECOVERY FROM ANOREXIA NERVOSA: A MIXED METHODS PHENOMENOLOGICAL STUDY

In contemporary Western society, we have been socialized to believe that physical health is the epitome of what it means to be healthy. Although cultural trends are shifting to be more inclusive of body sizes, we are still dominated by a societal view that thin bodies are equated with high social status and larger bodies with low social status (Saguy & Gruys, 2010). Since the leading causes of death in the United States (i.e., heart disease, diabetes; Kochanek et al., 2019) are largely attributed to behavioral choices (e.g., poor diet, sedentary lifestyles; Mokdad, 2004) and associated with overweight, the public health solution has been to target physical health (i.e., body mass index; healthier diets; Chan & Woo, 2010). Due to the rising rates of obesity in the U.S. (Hales et al., 2020) and increased risk of chronic health conditions associated with obesity (National Heart, Lung, and Blood Institute, n.d.), health professionals typically recommend weight loss for individuals with a higher body mass index ( $\geq 25$ ). Unfortunately, this myopic focus on body mass index as a measurement of physical health has its limitations (Nuttall, 2015). Societal messages about healthy eating and physical activity have produced inadvertent outcomes such as weight stigma, fat shaming, poor body image, and eating disorders (Ramos Salas, 2015).

Although public health experts and eating disorder professionals have attempted to reconcile the tension that exists between public health messages aimed at obesity prevention and eating disorders (Neumark-Sztainer, 2005, 2009; Schwartz & Henderson, 2009), a societal preoccupation with food and body shape/size prevails. Within the past decade, making healthier lifestyle changes—as opposed to sticking to a diet—has become an increasingly more popular trend among U.S. consumers (The NPD Group, 2020). Although ‘dieting’ is a less favorable

term, one does not have to be following a diet to be a part of diet culture— a system of beliefs and values that elevates physical health by attaching morality to food choices, eating behaviors, and physical appearance (Morris, 2020)—it is endemic to American society (Harrison, 2018, 2019; Trollope-Kumar, 2020).

Diet culture has played a significant role in forcing the dieting industry to move toward selling “health and wellness” (Chen, 2016). As of 2018, the wellness industry was worth \$4.2 trillion with increasing projected growth (Global Wellness Institute, 2018). Unfortunately, diet culture perpetuates the societal elevation of physical health as the epitome of what it means to be healthy (Trollope-Kumar, 2020) and spreads myths about nutrition and physical activity (National Institute of Diabetes and Digestive and Kidney Diseases, 2017) by pathologizing larger body sizes, encouraging external rules of what, when, and how much to eat, and suggesting body movement as punishment for or prevention of becoming fat (Chastain, 2019). For this reason, diet culture has been related to a system of oppression (Harrison, 2018)—by promoting weight loss in order to achieve a higher status.

Though understudied, the link between diet culture and eating disorders, such as anorexia nervosa (AN)—the focus of this current study—is not far-reaching (Schiavo-Campo, 2021). AN is a biopsychosocial-spiritual (BPSS) illness (Culbert et al., 2015; Stockford et al., 2019) defined by restriction of energy intake leading to significantly low body weight, intense fear of gaining weight or becoming ‘fat’, and body weight or shape disturbance (American Psychiatric Association [APA], 2013). As a BPSS illness, individuals have reported that recovering from AN is not limited to weight restoration or symptom management (Kenny et al., 2020), but includes attending to other aspects of health such as the psychosocial (i.e., interplay of cognitive, behavioral, and relational dynamics) and psychospiritual (i.e., cognitive and experiential

meaning making; Smethurst & Kuss, 2018; Stockford et al., 2019). Recovering from AN is also fraught with challenges and barriers, including but not limited to, mental health concerns (Kaye et al., 2008), societal ideals/standards, and maladaptive beliefs regarding eating and appearance (Smethurst & Kuss, 2018; Smith et al., 2016). Since diet culture promotes weight loss and elevates certain body types, it is likely to increase risk for developing AN and perpetuating symptoms of AN (Morris, 2020). As a sociocultural phenomenon, the values and beliefs associated with diet culture (e.g., thin ideal, weight stigma, external rules of what, when, and how much to eat) pass through social contexts and interactions and can become internalized into one's own belief system (Morris, 2020).

Given the societal focus on food, weight, and body size/shape and paucity of diet culture research, this current study aimed to close a gap in recovery research by exploring the lived experience of diet culture for individuals in recovery from AN. Since risk of relapse is particularly high within the first year following treatment for AN (Khalsa et al., 2017) and recent evidence suggests that only a minority of patients with AN may fully recover (Franko et al., 2018), it is important to understand the phenomenological experience of diet culture in recovery. The primary research question for the current study is: "How do individuals in recovery from AN experience diet culture?" The secondary research question is theory-driven and asks: "What are the BPSS experiences of diet culture for individuals in recovery from AN?" These questions were derived from a phenomenological qualitative approach (Smith et al., 2009) and theoretically-grounded.

### **Theoretical Orientation**

An integrated theoretical approach of social cognitive theory (SCT; Bandura, 1986, 1999) and the BPSS framework (Engel, 1977, 1980; Wright et al., 1996) ground this study. The main

research question is grounded in SCT and the secondary research question is grounded in the BPSS framework. SCT is based on reciprocal determinism (i.e., triadic interplay of person, environment, and behaviors), which refers to the dynamic interplay between personal (e.g., self-efficacy, knowledge, outcome expectations) and environmental (e.g., cultural beliefs/norms, social support, observational learning) factors and their mutual influence on health (Bandura, 1986, 1999). Said differently, this theory explains how health behaviors (i.e., health-enhancing or health-compromising) are influenced by how a person interacts with their environment. This theory helps to explain how individuals in recovery from AN are exposed to broader cultural beliefs and values about what it means to be healthy by observing behaviors related to food choices, eating patterns, and body movement or physical activity within their environment (e.g., home, school/work, social media).

Built upon general system theory (von Bertalanffy, 1968), the BPSS framework explains how multiple systems (e.g., community, family, two-person, person) interact and are involved in influencing the health and well-being of an individual, partnership, or family system. This framework also includes the role of spirituality (i.e., belief systems; Wright et al., 1996) as it relates to health and coping with illness. Stated simply, health is multifaceted and holistic and each domain of health (i.e., biological, psychological, social, and spiritual) merits assessment and treatment. This framework helps to conceptualize that (1) every aspect of health is interrelated, (2) each domain is of equal importance and value, and (3) diet culture can have an effect on the entirety of health (i.e., BPSS).

Integrated together, the BPSS framework (Engel, 1977, 1980; Wright et al., 1996) and social cognitive theory (Bandura, 1986, 1999) explain how individuals in recovery from AN may be at risk for internalizing diet culture beliefs and values by observing behaviors related to food

choices, eating patterns, and body movement or physical activity within their environment (e.g., home, school/work, social media). Since a person in recovery is embedded within an environmental and sociocultural context, larger systemic influences are likely to overlay their BPSS health experience in recovery.

## **Literature Review**

### **Diet Culture**

Within the past few years, diet culture has been recognized as a system of beliefs, values, and meanings that promotes physical health by equating thinness, muscularity, and particular body shapes, food choices, and eating behaviors with morality (Harrison, 2018; Morris, 2020). This system elevates individuals with thin bodies (thin privilege) and pathologizes (fat shames) individuals with larger bodies. Though diet culture is guised as “health and wellness” (Chen, 2016), the evidence of weight loss efforts in the U.S. indicates a societal drive focused on dietary restrictions. In fact, over the last few years, 49.7% of young adults (aged 20-39 years; Martin et al., 2018) and 37.6% of adolescents (aged 16-19 years; McDow et al., 2019) in the U.S. reported attempting to lose weight. Among those trying to lose weight, 25% report adhering to a diet plan, 16% report following their “own diet” (i.e., closely monitoring food intake), and nearly 10% follow the ketogenic diet (originally used in the 1920s to treat pediatric epilepsy; Wheless, 2008) and intermittent fasting (i.e., cycle of fasting and eating; The NPD Group, 2020). This is not only demonstrated in the growth of the weight loss market in the U.S., which experienced a 4% revenue increase to \$72 billion since 2018 (LaRosa, 2019), but also the global weight loss market which is projected to grow from \$254.9 billion in 2021 to \$377.3 billion by 2026 (Research and Markets, 2021). This market is far-reaching—food and beverage, sports and fitness, cosmetics, and healthcare. In fact, the pharmaceutical market for obesity drugs in the

U.S. increased from \$877.7 million in 2018 to \$964.8 million in 2019, and is projected to increase in value over the next five years (Fortune Business Insights, 2021).

Fortunately, within the past decade, a movement called Health at Every Size has grown in response to the cultural stigma and bias that has increased body shame and fat phobia, including the mistreatment of individuals living with obesity (Penney & Kirk, 2015). The Health at Every Size movement is attempting to shift the societal focus from weight to health, emphasize intuitive eating, body acceptance, and physical activity for movement and health rather than shape and weight. This movement also attempts to fight against diet culture. In recent years, diet culture has been given more meaning, particularly among those who challenge it. Despite widespread criticism, anti-diet culture advocates are not anti-health or anti-medical nutrition therapy (Harrison, 2018); rather, they are activists attempting to dismantle and expose the myths and misconceptions about health and what it means to be healthy that are perpetuated by diet culture. Although there are anti-diet culture advocates on social media working to challenge the beliefs and values perpetuated by diet culture (James, 2020), harmful online content relevant to eating disorders continues to exist (e.g., pro-Anorexia websites, thinspiration; Christodoulou, 2012; Saul & Rodgers, 2018). According to a recent report, companies promoting weight loss will target social media and influencers to reach Generation Z—the future generation of dieters (LaRosa, 2019).

## **Social Media**

For years, social media has been more than social networking and connecting with friends and family, it has served as a source of health information and platform for marketing (Perrin, 2015; Powell et al., 2011). Not all health information circulating on social media is beneficial. Some content is pro-eating disorder—going as far as to promote the belief that AN is

a life choice and not a mental illness, and have sought to recruit other members in their community (Rodgers et al., 2012). Although the effects of social media on mental health can be both positive and negative (Sharma et al., 2020), the amount of time a person engages with it makes a significant difference. Indeed, previous researchers have shown that excessive social media use is associated with negative mental health outcomes that overlap with eating disorders (e.g., anxiety, depression, eating concerns, body dissatisfaction, poor self-esteem, social comparison; Fardouly & Vartanian, 2016; Glaser et al., 2018; Sherlock & Wagstaff, 2019; Sidani et al., 2016).

Within the past decade, researchers have examined the association between social media use, media content, and disordered eating/eating disorders. Ubiquitously, they have demonstrated that excessive media use, including a higher number of social media accounts, was associated with disordered eating cognitions and behaviors, body dissatisfaction, internalization of appearance ideals and social comparison (Rodgers et al., 2020; Saunders & Eaton, 2018; Wilksch et al., 2020). What's more, the type of content (e.g., fitspiration or #fitspo and thinspiration or #thinspo) with which individuals interact can be particularly harmful for perpetuating the thin or muscular ideal and increasing body dissatisfaction. Fitspiration and thinspiration seem to have different goals—fitspiration content aims to promote healthier living by inspiring individuals to eat healthy and exercise whereas thinspiration content focuses on thinness and eating disorders/disordered eating. Despite their different aims, fitspiration and thinspiration content promote objectification of bodies, guilt-induced messages about body/weight, weight stigmatization, dieting or restrictive eating (Alberga et al., 2018; Boepple & Thompson, 2016). Not only does social media serve as a platform for body or food-focused curated content but also a transmitter of diet culture beliefs and values by perpetuating body type

ideals and social comparison. For individuals who engage with social media, this environment can complicate the AN recovery experience.

## **Recovery Experiences**

### ***Psychosocial Implications***

Previous researchers have highlighted the psychosocial experiences of AN and recovering from AN. Some women in recovery have reported withdrawing from friends, family, and activities and loss of connection from others, leading to feelings of guilt, low self-esteem, and anxiety (Smethurst & Kuss, 2018). For some women with lifetime AN, social detachment leads to feelings of invisibility (Williams et al., 2016). According to some adolescents' experience of treatment and recovery, feeling polarized by siblings, learning negative coping strategies from peers, doubting parent willingness to support, and coercive or controlling treatment staff are psychosocial hinderances to recovery (Bezance & Holliday, 2013). By contrast, others in recovery from AN have reported that re-engagement with meaningful relationships fuels recovery (Allison, 2021; Stockford et al., 2019). Indeed, a supportive relationship with a friend or partner and re-establishment of interpersonal connections has been identified as a major contributor to recovery (Smethurst & Kuss, 2018; Tozzi et al., 2003). Not only were supportive relationships the driving force in recovery (Tozzi et al., 2003), but also the impetus for starting recovery, maintaining healthy eating, and coping with anxieties (Smethurst & Kuss, 2018). Researchers have also demonstrated the psychospiritual experience associated with AN and recovering from AN.

### ***Psychospiritual Implications***

Previous researchers have shown how recovering from AN involves making meaning out of the illness experience. For some women, recovering from AN means more than returning to a

pre-illness state—it is a reclamation of their lives from AN and the effects of AN (Conti, 2018). According to a recent systematic review and meta-synthesis of qualitative studies, recovering from AN is largely about the *sense of self* (i.e., dealing with a fragmented sense of self, reclamation of self, rebuilding identity, and self-acceptance; Stockford et al., 2019). For decades, AN has been characterized as more than just an illness but also an identity (Rich, 2006). Individuals in recovery from AN have reported that it took over their ‘real selves’ (Williams et al., 2016) or obtained control (Williams & Reid, 2012), and became part of or completely changed their identity (Williams et al., 2016; Williams & Reid, 2012) to the extent they experienced no sense of self (Stockford et al., 2019). For women with lifetime AN, the taking over of their ‘real selves’ served to not only maintain the illness, but also fueled their fear of letting go of the illness and “being no one without AN” (Williams et al., 2016). For some, recovery is seen as a complicated grief process and imbued with fear as they work to give up AN (Conti, 2018; Williams et al., 2016). These enumerated accounts highlight the process of making meaning out of an illness experience and what it means to recover from it. This section also underscores the need to address psychospiritual health as it relates to recovery and relapse prevention. The following section describes the methodology of the current study.

## **Methods**

### **Data Collection and Procedures**

A pilot interview was completed prior to the current study to test the interview questions. Pilot studies are recommended to refine qualitative research approaches (e.g., data collection, interview questions) and anticipate problems or risks (e.g., researcher bias; Creswell & Poth, 2018). The pilot interview demonstrated suitability of the current study’s primary and secondary research questions and helped to refine the interview questions and suggested the need for a brief

quantitative survey to understand more about interviewees. Except for the addition of a survey, there were minor amendments to the interview schedule, and therefore, the preliminary data were embedded into the qualitative analysis of the current study (Creswell & Poth, 2018).

To be included in the study, participants had to be (1) at least 18 years of age or older and (2) not have an active eating disorder as determined by the participant. The sample was recruited from across the United States through purposive and snowball sampling (Heckathorn, 2011). Informed consent was collected at the time of the survey. Seven participants completed the online survey and eight completed the (virtual) in-depth interview. Each participant was compensated with a \$20 Amazon gift card upon completion of both the survey and interview. Both the pilot interview and current study were approved by the principal investigator's Institutional Review Board (see Appendix A).

### ***Refinement of Eligibility***

A revision of the eligibility criteria was made to be more inclusive and consistent with the language within the informed consent (i.e., individuals 18 years or older and no active eating disorder). Prior to this amendment, there was another layer that required participants to self-identify as no longer meeting *DSM-5* criteria (APA, 2013; e.g., *Most of the time I do not feel disturbed or in distress about my body weight or shape, etc.*). Unfortunately, this proved to be a barrier and the principal investigator, under the guidance of her major professor, removed the *DSM-5* eligibility criteria (APA, 2013). This action aligned with a previous researcher's findings indicating that some women in recovery from AN need to negotiate their subjective experiences of recovery on their own terms rather than be confined to the dominant medical discourse centered around the presence and absence of an illness (Conti, 2018). In sum, hinging on narrow

criteria excluded individuals for which the study was intended, but broad criteria allowed for the full spectrum of recovery experiences.

## **Measures**

### ***Demographics***

The survey collected social location information (i.e., age, race, ethnicity, gender identity, married/partnered, employment/occupational role, ability status) and other relevant information (i.e., age when first diagnosed with AN, time [months or years] in recovery, and if or when they relapsed; see Appendix B). Participants rated their sense of separation from AN on a 5-point Likert scale (from 1 for strongly disagree to 5 for strongly agree). Higher scores indicated separation from AN and lower scores indicated no separation from AN. Relational conflict as it pertains to food choices, eating behaviors, and physical appearance was also measured on a 5-point Likert scale (from 1 for strongly disagree to 5 for strongly agree). Higher scores indicated absence of conflict and lower scores indicated presence of conflict.

### ***Internalization of Diet Culture***

Internalized Diet Culture Scale (IDCS; Morris, 2020) measured the internalization of diet culture (i.e., degree of accepting broader cultural beliefs and standards of eating practices and physical appearance as one's own personal beliefs and standards). The scale contains 20 items and is measured on a 5-point Likert scale (from 1 for strongly disagree to 5 for strongly agree). Higher scores indicated a higher degree of internalization of diet culture and lower scores indicated a lower degree of internalization of diet culture. The IDCS includes four subdimensions. The categories include (1) Judgment of Self (i.e., own moral character based on diet, eating behaviors, or physical appearance resulting in feelings of guilt or shame), (2) Judgment of Others (i.e., others' moral character or worthiness based on diet, eating behaviors,

or physical appearance), (3) Overvaluing Physical Appearance (i.e., overemphasizing the importance of body size as it relates to health and wellness), and (4) Strictness (i.e., setting inflexible rules regarding one's own food consumption; Morris, 2020). The scale has been validated with a community-based sample but further testing is needed for further evidence of its psychometric generalizability (Morris, 2020). The internal consistency for the current sample is 0.893, which demonstrates good reliability of the scale (Tavakol & Dennick, 2011).

### ***Family Functioning***

Family functioning was measured with the shortened version of the General Functioning Subscale (12-items) of the Family Assessment Device (GF12-FAD; Boterhoven de Haan et al., 2015). The scale has been validated and is a reliable tool for measuring overall family functioning. Six items of the GF12-FAD measure healthy family functioning and six items reflect unhealthy functioning. Scoring is on a 5-point Likert scale (from 1 for strongly agree to 5 for strongly disagree) with the scale for the negatively worded items reversed. Higher scores indicate worse family functioning and lower scores indicate better family functioning. Items were reverse coded to perform Cronbach's alpha. The internal consistency for the current sample is 0.821, which demonstrates good reliability (Tavakol & Dennick, 2011).

### **Data Analysis**

This study followed an embedded mixed methods design with a dominant qualitative approach (Creswell, 2015). The qualitative analysis approach was informed by interpretative phenomenological analysis (IPA; Smith et al., 2009). IPA has origins in the field of health psychology as a method to understand experiential and qualitative health experiences (Smith et al., 2009) and is becoming an increasingly more popular approach across other fields of study in order to understand individual experiences related to the human condition (Smith et al., 2009).

Key theoretical underpinnings of IPA include phenomenology (i.e., study of experience), hermeneutics (i.e., theory of interpretation), and idiography (i.e., study of the individual; Smith et al., 2009). This approach aims to give voice and meaning to the subjective and inner experience of individuals (Larkin et al., 2006; Smith & Shinebourne, 2012). This approach was used for this study because it is important to gain a better understanding of the experience of diet culture for individuals in recovery from AN given the absence of research around this phenomenon.

Since IPA research aims to be more inductive than deductive, the primary research question for this study was epistemological and process-oriented in order to avoid “*a priori* theoretical constructs upon the phenomena” (Smith et al., 2009, p. 47). The secondary research question was theory-driven (Smith et al., 2009). This recommendation by Smith et al. (2009) was followed in this study as evidenced by the primary and secondary research questions.

Quantitative analysis took place in SPSS Version 28 and included (1) cleaning the survey data, (2) reverse scoring the 6-items from the GF12-FAD (Boterhoven de Haan et al., 2015), (3) computing new variables for the IDCS and GF12-FAD, (4) performing frequency and descriptive statistics (e.g., means, standard deviations), (5) testing reliability of survey items for the current study’s sample. Due to the small sample size, the quantitative analyses were primarily exploratory and used to inform the qualitative analyses.

Qualitative analysis took place in NVivo and Microsoft Excel. NVivo was primarily used for organizing the data, cleaning the interview transcripts, memoing, and preliminary (first cycle) coding. Microsoft Excel was used for second iteration coding, which is a technique that categorizes initial codes by grouping related labels (Saldaña, 2016). The initial codebook was created based on the interview topics. There were 13 initial codes. Some data were coded twice

when the participants' descriptions fit with more than one code. After initial codes were created, the principal investigator performed the qualitative data analysis.

The steps of the qualitative analysis were IPA-informed and included (1) reading and re-reading, (2) initial noting (e.g., descriptive, conceptual comments, deconstruction), (3) developing emergent themes, (4) searching for connections across emergent themes, (5) moving to next case, and (6) looking for patterns across cases (Smith et al., 2009). As similar and different descriptions emerged across the data and superordinate and subordinate themes appeared, this gave way to the unfolding of the interpretative narrative. IPA research aims to integrate both the participants' sense of their lived experience as well as the researchers' attempt in understanding how the participants' make sense of their experience (Creswell & Poth, 2018; Smith et al., 2009). This process was made evident in the current study by the weaving of participant quotes into the written narrative to demonstrate connection to the themes and highlight the collection of unique experiences.

In some instances, the principal investigator diverged from IPA to adopt other qualitative approaches. For example, second iteration coding is a technique which was used to help refine the initial codebook and included a mixture of codes from other qualitative approaches (e.g., In Vivo, process codes; Saldaña, 2016). Coding also consisted of observing patterns (Saldaña, 2016) rather than doing a line-by-line analysis (Smith et al., 2009). According to Saldaña (2016), not every datum requires its own unique code, and therefore, the coding approach for the current study was more like lumping, not splitting (Saldaña, 2016). In addition, this study leaned on a theoretical model (see Figure 1 in Chapter 4) to guide the analysis and interpretative narrative rather than following an inductive approach (Smith et al., 2009). Overall, adding other qualitative methods to the main IPA approach served to facilitate the analytical process.

Suspending judgments and setting aside personal experiences—known as “epoche” or bracketing—is an important process of phenomenological research so investigators can have a fresh perspective of the phenomenon (Creswell & Poth, 2018; Moustakas, 1994). The principal investigator is a female with no history of being diagnosed with AN or being in recovery from AN, but has close relationships with others who have been diagnosed and are in active recovery. The principal investigator is also a medical family therapist who works with individuals with various disordered eating/eating disorders, including weight-related concerns. Setting aside personal experiences also included a level of self-awareness to dialogue about observations and biases with the research team (i.e., committee members). The following section contains a summary of the participant characteristics and the quantitative and qualitative results.

## **Results**

### **Demographics**

The participants who completed the survey identified as cisgender woman ( $n = 7$ ) and ranged in age from 30 to 52 ( $M = 34.43$ ,  $SD = 8.14$ ). Most participants identified as White ( $n = 7$ ) and non-Hispanic/Latino/a ( $n = 6$ ) and one identified as Hispanic/Latino/a. All identified as being in a romantic partnership ( $n = 7$ ). Occupations varied from mother ( $n = 1$ ), attorney ( $n = 1$ ), college professor ( $n = 1$ ), intake counselor at an eating disorder treatment center ( $n = 1$ ), booker ( $n = 1$ ), and therapist ( $n = 3$ ). Although demographics were not collected during the pilot interview, the participant revealed their occupation as a therapist within their interview. Most participants indicated being able-bodied ( $n = 6$ ) and one participant indicated experiencing chronic pain from severe scoliosis. Four participants indicated more than one current mental health conditions from a list provided within the survey. The majority indicated Generalized Anxiety Disorder ( $n = 3$ ) and Major Depressive Disorder ( $n = 3$ ), and fewer marked Obsessive-

Compulsive Disorder ( $n = 2$ ), Posttraumatic Stress Disorder ( $n = 2$ ), other (i.e., low grade depression;  $n = 1$ ), and none ( $n = 1$ ). Time in recovery was broad and varied among the participants from one to two months ( $n = 2$ ) to 36 years ( $n = 1$ ). Additional sample characteristics are shown in Table 1.

## **Quantitative Results**

### ***Internalization of Diet Culture***

The degree of internalization of diet culture varied widely between participants—ranging from 26 to 84—bringing the overall level of internalization closer to the average ( $M = 52.14$ ,  $SD = 19.05$ ; see Table 1). Simply put, when all scores were combined the level of internalization was not high or low. Interestingly, the highest item scores on the IDCS were Judgment of Self items. Five participants indicated feeling like a lesser person when eating unhealthy food ( $M = 4.00$ ), feeling ashamed when they are above a certain body weight ( $M = 3.57$ ), and feeling guilty when eating more than intended ( $M = 3.86$ ). The lowest item scores were Judgment of Others with only one participant reporting uncertainty (i.e., undecided) for telling a lot about a person's morality by their appearance ( $M = 1.43$ ) and physically fit individuals are worthier of respect ( $M = 1.43$ ). The four subscales were compared and results demonstrated that the level of internalization was highest in Judgment of Self ( $M = 17.43$ ,  $SD = 6.32$ ), followed by Strictness ( $M = 13.71$ ,  $SD = 4.07$ ) then Overvaluing Physical Appearance ( $M = 12.71$ ,  $SD = 7.74$ ), and lastly, Judgment of Others ( $M = 8.29$ ,  $SD = 4.31$ ).

### ***Family Functioning***

Results from the survey indicated mixed healthy and unhealthy family functioning with an elevated level of unhealthy dynamics ( $M = 37.43$ ,  $SD = 3.59$ ; see Table 1). Unhealthier dynamics had to do with low support, communication difficulties, and negative emotions. For

example, five participants indicated low family support during times of crisis ( $M = 3.57$ ) and four participants indicated avoiding discussing fears and concerns ( $M = 3.57$ ), difficulty planning family activities due to misunderstanding ( $M = 3.57$ ), and experiencing lots of bad feelings in their family ( $M = 3.43$ ). However, five participants expressed getting along well ( $M = 2.43$ ) and four expressed being able to make decisions about how to solve problems ( $M = 2.57$ ).

### **Qualitative Results**

There were five superordinate themes and two subordinate themes (see Table 2). The five superordinate themes were vulnerability of self and others, isomorphic to AN, internalization vs. externalization, intense emotional experiences, and redefining health. The two subordinate themes were control vs. personal agency and social and family culture. Control vs. personal agency was subordinate to isomorphic to AN because it was part of how they isomorphically described their experience of diet culture to AN. Social and family culture was subordinate to intense emotional experiences because it was within those contexts their emotional responses were primarily evoked. Patterns of convergence and divergence and the process of meaning making through dialogue are highlighted.

#### ***Vulnerability of Self and Others***

One of the major themes that surfaced across the interviews was vulnerability of self and others. When participants described what diet culture meant to them as a person in recovery from AN, the common discourse was around a state of being exposed to a harmful and threatening system. As one participant reflected, "...I feel like I have to work to go against what diet culture has defined is the norm. And it's kind of everywhere, and so I am constantly having to be aware of those things, and actively choosing not to participate in that...falling into that trap again and so I think it's a dangerous thing...". Four participants talked about the fear that diet culture

instills in them regarding making food choices, including the fear of going against what diet culture elevates as superior. As one participant shared:

...[I]f I gain weight, if I do what my treatment team is telling me to do or that I have to do to be healthy and get better, then that also means that I'm jeopardizing my worth and value as a person because I'm subjecting myself to other people judging me or thinking less of me because my body doesn't necessarily fit the thin ideal or what culture/society says is good and beautiful. So I think there's this deep fear. Diet culture was this huge fear monster that made it really, really, really hard to recover.

This vulnerability also came through as fear of being harmed by AN again as a result of constant exposure to triggers while trying to recover from an addictive disorder. While the experience feels addicting, it is not the same as a drug or alcohol addiction as a couple of participants noted, "...unlike drug addicts or alcoholics we can't ever get away from food" and "you don't have to literally look at drugs three times a day". Not only do they face their trigger every day, they face it multiple times a day, which feels threatening because as two participants recalled, they do not want to "fall victim" to it again. As another participant described, "It was the community that we were all on the same team fighting against food or something... but now it's the enemy... It's like getting ads for heroin".

This vulnerability is not limited to the experiential memory of their illness—it crosses over into social location (e.g., gender, sexual orientation, romantic partner). Most participants ( $n = 5$ ) described the vulnerability of women in terms of being targeted by diet culture. They described gender expectations (e.g., striving to achieve a certain standard, look a certain way) and the overall objectification of female bodies. One participant described it this way:

I think diet culture is heavily aimed at women... thin white women. And when I was growing up, the image was Kate Moss and even Edie Sedgwick had like a comeback in the pro Ana thing. It was like, this is kind of what's expected of you in order to project an ambitious, approachable female person. And although I don't think that my actual eating disorder was me trying to do that, I think, again, it justified the behavior. The end result of looking thin, looking a certain way was like, well, see, this is not bad that I'm weighing my food and barfing because this is the effect. This is what people want.

A couple described how diet culture held them back from being authentic versions of themselves by keeping them stuck in binaries (i.e., gender and sexual identity) and self-restrained (i.e., partnered sex). As one participant recalled, “I think diet culture kept me from experiencing myself, my individuality, and exploring that and coming up with my own ways to express myself and show up in the world...it kept a cover on my queerness in a way, if that makes sense, just by keeping me stuck in binaries and things.” The other reflected on her experience in partnered sex: “...there's definitely an element of sometimes feeling I can't access that [“sexy person”] because I don't feel like I live up to the image that diet culture presents a sexy person looks like.”

In response to feeling vulnerable, the common response among participants was to protect self and others by fighting, exposing, and rejecting this system. For most participants ( $n = 5$ ), recovery entails fighting against this cultural system. Four specifically expressed fears and concerns regarding the vulnerability of others, particularly children and adolescents, and their role to protect them from harmful and dangerous beliefs that perpetuate rigid rules around food and eating and elevate certain body types. As one participant reflected:

...when I see people being treated in a way that is marginalizing a group of people or oppressing a group of people, then I become very heated and frustrated and angry about that...and seeing how this is impacting people daily and just how so much of the fears of body changes and all of that is showing up... when 12-year-old girls who are going through puberty and getting their periods and needing to be gaining weight are absolutely terrified of what that might mean for them socially...

A couple of participants talked about fighting diet culture by educating self and others in terms of discussing the function of food. As one participant described it, “I see it in terms of these foods are all necessary and why are they necessary and what role do they play in all these functions in your life have really helped me and taken away the fear of some of those things.”

Three participants discussed removing labels. For example, “...it means protecting my daughters

from negative thoughts and associations around food and labeling”, “...how I talk about food in terms of I don't talk about there's no good foods or bad foods there's not clean foods or dirty food... like these labels”, and “...nourish [my body] with things that are good for it without having that label of good or bad food...”. A few ( $n = 3$ ) also discussed admonishing restrictive or obsessive eating practices observed with friends or family, which can sometimes be met with pushback. As one recalled, “But even in a family that should understand me saying, ‘hey intermittent fasting is actually not healthy and it makes a ton of sense why you're bingeing at night’, my family looks at me like I have 12 heads”.

### ***Isomorphic to AN***

Participants isomorphically described their experience of diet culture to their experiences of AN. Diet culture produces a fear and anxiety about food choices and body image similar to that of AN. One participant emotionally processed this as “a culture of fear that [she] can't live up to and can't control...so anything that might give rise to those beliefs and behaviors, it upsets [her]”. Another participant similarly described it, but also expressed unfairness: “It's frustrating because everybody else gets to believe these and not be sick. But it's a culture of everybody being sick, but I'm the only one who has to change my ways.” Participants experienced the relationship between diet culture and AN as either contributing ( $n = 6$ ) or not contributing ( $n = 2$ ). Most participants ( $n = 6$ ) noted that diet culture influenced certain eating disorder behaviors such as severe restriction, over-exercising, constant checking of social media, and overall obsession around food. As one articulated, “Diet culture is all about food rules, eating at certain times or eating certain things, only eating this and not being intuitive. And so, it influenced my behaviors to deny my cues and to restrict and to obsess about food.” Although a couple did not recognize the existence or role of diet culture at the onset of their illness, they described parallel

experiences to the other participants in terms of the function of AN and its symptoms (i.e., need for control, coping with trauma).

Even though the participants identified the function of their eating disorder behaviors as more than adhering to food rules or striving to live up to cultural standards/values, the influence of diet culture was nonetheless evident. As one participant shared, “[AN] was a means of denying emotion or other fear...a way of control, but it was still diet culture sending messages of being in X body, being in a larger body will not equate with contentment or peace.” For another participant, diet culture was a means of meeting deep emotional needs: “...I just became so hyper focused on I must do this if I'm going to be loved and accepted and seen as beautiful and worthy in the eyes of others...I must shrink.” Similar to AN, adhering to dietary restriction was a coping mechanism, which not only worsened over time but was also experienced as her eating disorder:

I followed the rules of the diet just like my parents did. But I just kept kind of increasing the stakes like, well, I could do it even better...I could do this amount and then I could do this and it was helping me cope with other life and trauma and stuff, but it was through that vehicle, it gave me...these steps. But there is no messaging of ‘this is when it's too much, this is when you should stop’. It's presented as...you keep getting higher and holier the more you stick with this...It also developed the fears, right, because there's a lot of foods that are off limits in those diets.

Most participants ( $n = 7$ ) shared a similar process when describing how diet culture not only encourages obsessive thinking about food, but also fuses with one's identity. As a couple pointed out, “There's a lot of belief around what you eat is who you are” and the belief that “you're going to be a better human being, you're going to be a better version of yourself if you eat this kind of food”. One participant described living with an eating disorder for over a decade without realizing it was an eating disorder: “I think even just being so caught up in diet culture it led to my diagnosis. Simply because I was blinded by diet culture. It kept me in this bubble with

blinders on to finding out that I actually was struggling with something that was pretty serious and I couldn't see past it to even see that help existed.” One participant summed up the isomorphic experience to AN well: “It's like the ED voice personified, like it is everywhere. And I feel like I have to bump up against it 40 times a day without seeking it out. And so it makes it so much harder to recover.”

**Control vs. Personal Agency.** The concept of “control” was brought up multiple times by nearly every participant ( $n = 7$ ). One participant described their experience of diet culture in terms of, “I can control my quote unquote health. If I do these certain things or follow this certain diet, I have control or predictability on the outcome or the happiness or wellness of my life, well-being of my life. I think it's an illusion of control” (sic). A few participants described their need to have control in stressful times and how food can be controlled. As many processed this experience of control, they expressed the harm of diet culture meeting their need to have control. One participant described following “clean eating” in recovery: “I went through orthorexia as a way of trying to recover from anorexia...the process of cutting out things triggered this need to continue doing this. And so I started cutting out one thing and then that led to another and it doesn't stop.” Another participant described how behaviors such as “restricting and motivation to exercise and eat ‘healthy’” are “associated with these qualities of self-control”. For most participants ( $n = 6$ ), when life felt out of control or stressful due to major life transitions (e.g., going away to college, moving, giving birth), diet culture played a role in a season or episode of relapse. As one recalled, “I was very determined not to fall into that category of gaining weight once you go away to college, and so that's kind of what started the behaviors to avoid gaining weight or just having control over my weight.” Although diet culture offers a means of control, five participants shared how this control keeps them in fear. For example, one

participant shared how “[her] life was completely ruled by that fear of what other people were doing and their food choices” and another described how fear led to a season of relapse: “...it was all of my fear foods that I was faced with, and so my brain was ‘well diet culture tells me that these foods are bad. These foods are demonized and if I eat these foods then I will get fat again’”.

For the younger participants ( $n = 6$ ), increasing personal agency in relation to diet culture has been an important process during recovery. Personal agency was expressed as being aware, noticing, shifting focus, and ultimately, opting out of diet culture. As one participant described this:

I think the big difference is recognizing that I can opt out. I think when I was really first diagnosed with anorexia and really, really struggling with that deep fear of weight gain, it was very much this passive "this is just the culture I live in there's nothing I can do about it. I don't have any power to push back on this because this is the macro cultural belief system, therefore, it has to be mine." And I think now being in recovery there's this deeper awareness that I get to opt out and it doesn't actually have to be how I view my body, it doesn't have to be how I view other people's bodies. I have a choice.

For the eldest participants ( $n = 2$ ), personal agency was expressed in other ways (e.g., understanding the function of their eating disorder behaviors, holding true to a personal value of eating healthy, and turning from external rules regarding eating or food choices).

### ***Internalization vs. Externalization***

More than half of the participants ( $n = 5$ ) described how diet culture beliefs and values assimilated into their own beliefs and values. One participant expressed being “knee deep” in it still and fused with her identity. One participant referred to this experience prior to recovery as “diet culture running through my veins” and another described it as believing “you are a better, more successful person if you can do these things right...if you weigh a certain amount, if you're thin enough and you are healthy and you are more attractive, more successful...you're going to

feel more valuable as a person if you can stick to these... constantly changing rules”. For most participants ( $n = 6$ ), a significant part of recovery involves an active and ongoing externalization of diet culture—a conscious separation of one’s own beliefs and values from diet culture. As one participant described, “I think one of the ways I've really dealt with my own internalized beliefs around diet culture and fat phobia is working hard to not make assumptions about people's bodies when I see them”. Similarly, another participant shared, “I think for me it’s been the shift in what I’m choosing to focus on because the same messages are still out there. Standards are still out there, but latching more on to...body neutrality piece and body acceptance because before I was just so focused on being the smallest I could be and trying to hit that standard”. This process not only allows them to question beliefs and values associated with diet culture, but also separate from it. One participant used a metaphor to describe this process of externalization: “Recovery feels like taking all of those bits of diet culture that are inside of you and putting them on a billboard instead so you can look at them versus them being a part of you”.

### ***Intense Emotional Experiences***

Experiencing diet culture in their environment or relationships evokes strong negative emotions among the participants such as anger ( $n = 5$ ), frustration ( $n = 5$ ), fear ( $n = 5$ ), shame ( $n = 5$ ), and sadness ( $n = 4$ ). One participant attributed the cause of feeling angry and frustrated to "...the idea that so many people in the world value something that could negatively impact your health so much.” A few ( $n = 3$ ) others attribute their emotional responses to the ignorance or lack of awareness of diet culture among some people. While most expressed secondary negative emotions, some used more emotional granularity such as feeling unfair/jealous ( $n = 3$ ) and misunderstood/alienated ( $n = 3$ ). In context of relationships, the emotional reaction stems from observations and interactions with other people (e.g., family members, friends). For example, a

few participants ( $n = 3$ ) expressed feeling a lack of fairness when observing others engaging in a fad diet or physical fitness. As one participant shared, “I wish I could do this super strict workout program or follow a certain meal plan or diet and I know that I'm not able to, and I think a part of me is just frustrated when I see other people doing it because it's that piece of me that's like well if they can do it, why can't I?” In context of personal exchanges, a few ( $n = 3$ ) expressed feeling alienated or misunderstood. As one participant who proactively educates others about diet culture recalled: “I feel misunderstood a lot of the time and that sucks, but I'm also willing to be misunderstood if it's going to help change lives and if it's going to help compensate for people's bodies to be treated with kindness and respect.” For most of the participants ( $n = 6$ ), their experience of diet culture overlaps with their identity/sense of self, beliefs, and values. For example, one participant said, “To choose the quote unquote...unhealthy option or the more ingredient option or the non-organic option feels like you are a bad mother”. Another reflected on the vastness of this experience in terms of their beliefs and view of self:

I mean it's absolutely contributed to feelings of worthlessness and shame and just this fundamental belief of who I am is not enough or who I am is not okay. And that there's always something I need to be doing to be earning that or achieving that...it was such a dagger at my sense of self and my sense of self-worth. How I saw myself was absolutely filtered through my image and what I looked like. I think it's deeply painful. I have had to work so hard to create a different way of viewing myself and it's taken years, like years, for me to get to the place that I am now to have the strength to believe that I'm worthy and enough, and still beautiful, even as my body changes, and even as I get wrinkles on my face. It's a fight, it's a fight to believe that I am beautiful and I'm enough.

These emotional experiences were relayed through their interactions or observations in their environment (e.g., social media, healthcare, grocery store) and with family or friends.

**Social and Family Culture.** Diet culture is observed in social and family contexts. Every participant spoke about their experience with diet culture in their social contexts with the majority experiencing diet culture through social media ( $n = 7$ ), healthcare settings (e.g., child

well visits, adult visits;  $n = 3$ ), and grocery stores ( $n = 2$ ). Other environments mentioned included coaching programs, gym/fitness culture, school setting, home, work, and airports. When participants ( $n = 3$ ) described encountering diet culture in these contexts, strong emotions such as invasive, deflating, and disempowering were expressed. As one participant described: “It feels like you’re being followed by it. You can’t escape it. When I’m feeling stronger, it’s infuriating and when I’m feeling weaker, it’s oppressive. Again, escapable”.

For some ( $n = 3$ ), social media is not only a channel of diet culture—it played a role in their eating disorder. Excessive use and checking accounts to find recipes or learn food choices of people with body types they idealized became a vicious cycle that reinforced their eating disorder. One participant described diet culture as the drug she sought out in social media: “I remember in high school there was like all these Tumblr accounts like pro Ana/ crazy shit like that, it was literally the thing that I sought out to affirm me and keep me going”. Interestingly, a couple participants shared how they have chosen to unfollow certain social media accounts or mute health content altogether and one participant deleted their social media accounts years prior to this study. Sometimes diet culture shows up in seemingly benign, yet harmful ways: “Social media is another environment that is pretty insidious because it’s always presented in terms of a person and their happiness and very carefully curated, and then they’re like, by the way, skinny tea is what’s caused this situation.”

Healthcare contexts were experienced in terms of providers using binary concepts about weight and nutrition (e.g., healthy versus unhealthy), a focus on weight and weight loss, and health magazines. As one participant recalled, this experience was reinforcing of her eating disorder: “...even at my kids’ well visits, we talk about weight and nutrition and the way that it’s presented is always healthy foods versus unhealthy foods. There’s never a discussion about

moderation or what foods do for you. God forbid, I've never been overweight, but I can imagine what that would be like in a medical context where that's the first and only thing that they would focus on. I never had a doctor question my health, but they were like, oh, you have low blood pressure. That's awesome. I'm literally dying.”

Familial and significant relationships were noted as important. Participants reflected on their family culture (i.e., family of origin and choice) in terms of their experiences with diet culture. For every participant, diet culture shows up in their relationships (e.g., friends, family, or partners) in varied and more or less obvious ways. Four participants reported family (of origin) environment as a conduit of diet culture through parents dieting and/or speaking openly about negative body talk. Regardless of the subtlety of the food rules or evidence of dieting behaviors, the modeling was remarkable: “As a kid, a child of dieters, it was the class I was trying to get a good grade in and they were the teachers”. For the others ( $n = 4$ ), diet culture either shows up more in their dynamics with their partners than their family of origin because of the ongoing challenge of addressing food avoidance/fears or by way of how they are understanding it: “It’s interesting to navigate conversations with friends and family and...have that knowledge and awareness of, ‘this is a really diet saturated conversation’”. More than half of the participants who completed the survey ( $n = 4$ ) also reported experiencing some conflict in their relationships as it relates to food, eating, and beliefs about their physical appearance ( $M = 2.86, SD = 1.77$ ).

Given their experience of diet culture in their own families, four participants mentioned being protective with their own children from negative thoughts and associations around food and labeling by modeling and setting boundaries around food and body talk. One parent described how she manages this intergenerational dynamic: "As a mom it feels like I have to do censorship. That's my role. I have to rewrite the narrative that's presented to them. And then I

have to justify that to other family members who would like to speak differently about food around them." As some participants relayed ( $n = 3$ ), when they challenge cultural norms about food or bodies in their families of origin, they experience relational conflict. As one reflected, this conflict stems from misunderstanding but creates a wide relational chasm:

"For my parents it's alienating because we're experiencing it so differently, it's like a big, big block...[my mom] doesn't even recognize her relationship with diet culture. She thinks she's being completely logical and sensible. And when I bring things up to her...she thinks that I overdo it...the way that I see it seems so foreign to them. And then to me, it feels like a rejection of me. They're embracing of diet culture feels like a rejection of me."

Whether inside or outside of their own families, most participants ( $n = 5$ ) view their role as educators/challengers of diet culture. As antagonists of diet culture, it is not surprising that half experience communication challenges with others regarding diet culture (e.g., "speaking a different language"). In context of having a platform to educate others, one recalled how divisive and emotionally exhausting it is to challenge culturally accepted norms that have become ingrained beliefs about food and body movement:

I feel like I'm always swimming upstream and I feel like people think I'm crazy for not subscribing to diet culture. The assumptions and the judgments that people make about you are 'well you don't care about health or you're promoting obesity'... It doesn't compute for people that these things are things that we can question and we can question them in a way that doesn't dismiss the role of nutrition and movement and health. But that's also a nuance that people can't see because of how black and white it is. If you are questioning these things, then this also means that you must be against people being healthy. And it makes me want to throw in the towel some times because it's hard. It's hard to swim upstream all the time and it's exhausting to advocate for something and to push back on something that is just so socially acceptable.

Overall, the experiences with diet culture in relational contexts were mixed. In addition to the negative experiences, six participants also shared positive experiences with friends/peers, partners, and coworkers who challenge diet culture including communities associated with the anti-diet culture movement and Health at Every Size movement. Communities that share similar

beliefs and values are validating as one shared: "...the anti-diet culture movement has been very helpful for me because it's like saying, 'you're right, this is not a healthy culture, you're not crazy for being angry about this'." Expressions of feeling reassured, helped, and lucky were shared as they reflected on these relationships. One participant articulated the duality of this experience: "It's both reassuring and freeing for my friends who are challenging it and who are living in freedom...But for people who are not challenging it and are kind of sucked into it, it's sad and frustrating."

### ***Redefining Health***

While every participant talked about the emphasis diet culture places on the body or physical health, every participant spoke about their health being more than their physical body. Health was expansive or holistic and inclusive of physical health, but with less focus on the physical aspects and more attention on emotional/mental health, relational health, and spiritual health (i.e., renewed sense of identity and flexible beliefs about food, eating, and exercise). As one participant said, "[Diet culture has] this very limited definition of health, equating to your physical body or physical state of being. That's just a component of health, the physical. To me, health is my emotional health, my relational health, my spiritual health. And how am I tending to each of those areas because those areas together makeup health and wellness". More than half of the participants ( $n = 5$ ) discussed the interconnectedness of mental and physical health and four emphasized "listening to their bodies" in more intuitive and caring or gentler ways (e.g., intuitive eating and "joyful" body movement). One participant shared, "I'm kind of unlearning these beliefs about exercise as a punishment and exercise to compensate. When you exercise, it has to be this really intense and long experience. Like you must feel like you're dying type of

experience for it to count. I'm unlearning all of that. I exercise because I want to move my body or because I know the mental and physical benefits of moving my body."

Five participants discussed the role of emotions and mental health such as emotion regulation and distress tolerance skills. These participants shared about the value in "recognizing pain and sitting with pain", "cop[ing] and express[ing] and evolv[ing] without having to do something physical to deal with it", accepting body changes, happiness, and stress management. Five participants discussed relational health in terms of serving other people, being a safe place for others, communicating their needs, connecting, being open-hearted, present-focused, healthy boundaries, relinquishing control and leaning into vulnerability. One participant shared, "The eating disorder takes away from connection, it did for me. And so well-being is me saying yes and being open hearted and present for the people around me..."

Finally, six participants discussed the role of spiritual health. Responses ranged from "self-forgetfulness", freedom from anxiety and obsessing about food/weight/body concerns, less rigid or restraining beliefs about food and exercise, focus on values, and adopting a more balanced/flexible attitude in life. Most of the participants who completed the survey ( $n = 5$ ) also reported a psychospiritual sense of separation from AN ( $M = 3.86$ ,  $SD = 1.07$ ). One participant not only emphasized the shift in focusing more on their spiritual health, including their belief in a Higher Power to ground their identity, but also the interconnectedness of every aspect of their health:

I have a sense of self and a deeper identity that goes far beyond anything that this culture or world tells me I am... it's a quiet confidence which then allows me to make those healthier decisions with how I care for my body. Caring for my body is caring for my soul... loving my family...implementing values...serving other people... if I'm prioritizing those things I'm going to think less about food. I'm going to care for myself so that I can do those things...I'm going to want to be taking up space in my brain to really pour into what I love and value and cherish.

Throughout each interview, a psychospiritual process was apparent. As diet culture has been named within the past five to six years, most participants ( $n = 6$ ) have experienced momentum in their recovery to reject diet culture. Actually, ‘naming’ diet culture has helped half of the participants understand what it means to them. For example, as one relayed, “So the fact that it's been named and given a definition has been actually very helpful in terms of being able to write it off or combat it.” Half of the participants ( $n = 4$ ) shared that staying aware and learning about diet culture are the most influential facilitators of their recovery. As one participant said, “Learning has been very influential because it helps me have a language to articulate why these things cannot work for me, why these things are not healthy for me.” One participant shared, “I think it's interesting to stay aware of diet culture as I am in recovery because the anger that it ignites in me is motivation to get better and overcome it, and also to help other people.” Indeed, learning about diet culture is empowering and protective because it equips them to reject a system that no longer aligns with their beliefs and value systems. As one participant described it: “...it's like pulling back the curtain. Without learning about these different diets and why they're toxic and why these beliefs are wrong, not only physically but also emotionally and mentally, having the reasoning helps me feel like I'm armed to deal with it...you don't know who your enemy is if you don't know about it.” For another participant, learning has solidified her recovery: “I think it helped me not want to go back because I was able at that point to just be like okay, these are values, and these are not values that are aligned with my values anymore and so I think it gives me in a way energy and strength to say I'm actually going to reject this in my life and I'm going to be a part of helping other people reject this too.”

## Discussion

An integrated theoretical orientation (BPSS framework [Engel, 1977, 1980; Wright et al., 1996] and SCT [Bandura, 1986, 1999]) and IPA (Smith et al., 2009) informed the overall guiding approach to explore the whole health experience of a sociocultural phenomenon for individuals in recovery from AN. Through open-ended questions (Smith et al., 2009), participants were invited into a meaning making process of their inner experiences—bringing the unconscious to the conscious (Larkin et al., 2006; Smith & Shinebourne, 2012). The essence of the participants’ experience of diet culture in recovery involved descriptions of vulnerability/exposure to a threat, AN personified, an illusion of control, inciting strong emotions, process of unlearning/rejecting, and an impetus for recovery. Only a few of the participants had become more actively aware to engage with diet culture as a system. A couple did not have a prior concept of diet culture, but this was not a barrier. Reflexivity proved to be rich and informative process as evidenced by the level of self-awareness and metacognition demonstrated by the participants in this study. This process was aligned with the study of phenomenology, which is less concerned with the meaning of concepts, but rather aims to retrospectively bring to awareness some experience lived through—or in this case as it relates to diet culture, continue to live through (van Manen, 2017). Embedding the survey responses into the analysis added another dimension to the overall findings, but due to the small sample size, were meant to be exploratory, not conclusive.

Applying an integrated theoretical framework (SCT [Bandura, 1986, 1999] and BPSS framework [Engel, 1977, 1980; Wright et al., 1996]) to the overall findings demonstrates that a sense of personal agency and self-determination in recovery is essential to reject diet culture—a sociocultural system that has the capacity to oppress all aspects of health. Before recovery, there

was a general lack of awareness of diet culture, which was masked by their internalization of it, and high levels of social comparison. Now, when they observe or encounter diet culture in their social contexts, they make a conscious decision to choose differently (e.g., choose the “less healthy” option because it is important for them to be inclusive of all foods in their recovery) than the norm, knowing this choice will have a positive outcome on their overall health and well-being.

Overall, the findings demonstrate that their experience of diet culture in recovery overlays their BPSS health and has the potential to be both oppressive and reinforcing of their recovery. The main contributions from the current study emphasize the experience of diet culture (1) parallels the participants’ experience of AN, (2) overlays psychosocial experiences, and (3) involves the dialectic experience of feeling both threatening and motivating to recovery. The next sections in the discussion will address strengths and limitations, clinical implications, and future research implications.

The quantitative results demonstrated the broad recovery experiences as they relate to the level of internalization of diet culture and family functioning. These results are exploratory and interpreted cautiously due to the risk of margin of error. The degree of internalization of diet culture varied from low to high among the participants, which was not surprising considering the broad recovery experiences. Practicing flexibility/less rigidity as it relates to food choices is challenging as evidenced by most participants reporting judging themselves for choosing “less healthy” food options. Recently, a researcher found that internalization of diet culture is positively related to disordered eating behaviors, thin idealization, weight bias internalization, fatphobia, and body shame and surveillance, while negatively related to intuitive eating, body satisfaction, flexible views of beauty, self-compassion, and self-esteem (Morris, 2020). The

range of scores demonstrated in the current study show that individuals in recovery may be at higher or lower risk of relapse depending on their level of internalization. The negative family dynamics reported by the study's participants matches previous research findings on family dynamics with AN (e.g., impairment in communication and affective involvement [Ciao et al., 2015] and high expressed emotion [Rienecke et al., 2016]). Despite challenging dynamics, participants also expressed positive family experiences (e.g., getting along well). Summarized next are the three main contributions from the current study.

First, diet culture overlays their physical and mental health because it parallels their experience of AN and increases their vulnerability to relapse. Their experience of diet culture feels like their experience of AN because it perpetuates cognitive distortions (e.g., rigidity, black and white thinking), body and social comparison, and maladaptive behaviors (e.g., restriction, over-exercising). Participants recalled experiences of body shame, feeling unloved or unaccepted, and self-denial through restriction or over-exercising, perpetuated by societal ideals about body size and shape. For the study's participants, diet culture offers a solution in the guise of health to handle anxiety, insecurity, and loss of control, which also parallels their experience of AN. Diet culture seems to have more influence around major life transitions and stressful events, which is unsurprising given the sense of security and safety that is jeopardized during these times. It is known that diet culture affirms rigid and restrictive eating disorder behaviors by encouraging external rules of what, when, and how much to eat, pathologizing larger bodies, and implying physical activity as punishment for or prevention of becoming fat (Chastain, 2019). Experiencing diet culture on a day-to-day basis not only complicates the participants' recovery, but also increases their psychological vulnerability to relapse. Others in recovery have expressed a similar sense of vulnerability (or exposure) during recovery as it relates to the loss of defenses

that AN provided (Piot et al., 2020). Since risk of relapse is high following treatment (Khalsa et al., 2017), individuals in recovery are susceptible to falling into patterns of disordered eating or other eating disorders (e.g., orthorexia nervosa). Other researchers have found that disordered eating provided women in recovery a sense of safety and were consistent with cultural values concerning healthy eating and gendered bodies (Musolino et al., 2016). Although Musolino et al. (2016) did not study diet culture, their findings support the experience relayed by the participants in this current study. What's more, nearly every participant in this current study indicated current mental health conditions (and some more than one), suggesting heightened mental health risk.

Second, diet culture is experienced psychosocially because it crosses over into relational dynamics and increases their sense of vulnerability for others. Though overall relational experiences with diet culture were mixed, the relational strain experienced in recovery persists as indicated in both survey and interview responses (e.g., conflict as it relates to food choices, eating behaviors, and body image, communication difficulties, negative emotionality). Most of the participants experience diet culture in their family environment (e.g., parental or partner dynamics), varying between positive (e.g., partners who help challenge food rules/avoidance) and negative (e.g., parental unawareness of diet culture) experiences. Positive relational experiences, whether with families, friends, or peers/colleagues, were tied to sharing similar beliefs and values and facilitative to recovery. Familial support (i.e., availability, reliance) during recovery is well-known (Piot et al., 2019); however, familial support as it relates to shared beliefs and values associated with diet culture is a new aspect worth exploring. Although these individuals are in recovery from AN, it is not surprising they continue to experience challenging family dynamics, particularly as it relates to food or body concerns.

An intergenerational pattern was observed as participants contrasted their family of origin experience (e.g., protagonists of diet culture) with their experience within their own families of choice (e.g., antagonists of diet culture). There was a common discourse around protecting the vulnerable (i.e., children and adolescents) from the harm of internalizing diet culture beliefs and values, which was unsurprising since half of the participants are parents and three are therapists. This drive to protect others may serve as a protective factor for these individuals in recovery since previous researchers have found that becoming pregnant or desiring to start a family fuels recovery and helps mature individuals out of the disorder (Tozzi et al., 2003). Social environments (e.g., social media) are major conduits of diet culture messages about weight, body sizes, and food.

The subtle yet pervasive presence of diet culture on social media has also been recognized by others. It is well-known that diet culture has a strong presence in online platforms via advertising, food blogs, and social media influencers since it manifests in many ways such as the “Eat Clean” movement (“good” versus “bad” food), fad diets (e.g., intermittent fasting), nutrition programs, diet products, weight-loss services (e.g., Weight Watchers), and physical fitness training programs (Trollope-Kumar, 2020). Not only do social media sites promote businesses such as the wellness industry by advertising weight loss products or services (Olof Lagrosen & Grundén, 2014), there is also curated content focused on food, eating practices, and body ideals (e.g., fitspiration or thinspiration). According to previous researchers, simply viewing this content on Instagram increases negative mood and body dissatisfaction among young women (Tiggemann & Zaccardo, 2015). As relayed by the participants in this current study, diet culture fuels body-related social comparison, which is not only strongly related to disordered eating, but also predictive of AN symptomatology (i.e., drive for thinness and body

dissatisfaction; Hamel et al., 2012). Regardless of the different aims behind food or body-focused content (i.e., promoting healthy eating and physical activity or showcasing thin bodies), both promote objectification of bodies, guilt-induced messages about body/weight, weight stigmatization, dieting or restrictive eating (Alberga et al., 2018; Boepple & Thompson, 2016) and are triggering for those with a history of disordered eating (Jennings et al., 2020). The participants in this current study who noted their use of social media was addictive also recognized how it influenced their symptoms and experience of diet culture. Other researchers have identified this phenomenon by demonstrating that disordered eating attitudes were positively associated with addiction to social networking sites and significantly correlated with the number of methods used to change body image, thin body ideal, and lower self-esteem (Aparicio-Martinez et al., 2019). As relayed by the participants, there are widespread efforts working to challenge harmful online content relevant to disordered eating and eating disorders. There are professional organizations (i.e., AN and Associated Disorders) and social media platforms (e.g., Pinterest and Tumblr) that have worked to ban harmful online content relevant to eating disorders (Rodgers et al., 2016). Online support groups (e.g., pro-recovery groups) also provide a safe space for individuals in recovery from AN seeking guidance and information (Eichhorn, 2008).

Interestingly, there was a notable difference between the eldest and youngest participants in terms of what diet culture meant to them and a similarity that crossed all ages. Contrary to the younger participants, the eldest participants did not recognize diet culture contributing to their eating disorder. Indeed, the younger participants (i.e., younger Millennials) used activist language and saw diet culture as a social justice issue whereas the eldest participants (i.e., older Millennial and Gen X'er) saw some issues as social concerns (e.g., gender expectations, societal

ideals, etc.) but did not express energy to fight or reject it. These differences may be attributed to the span of ages represented in the study's sample and shared social experiences associated with their generational cohorts. As the study's younger participants indicated, the naming of diet culture in the past five to six years has given rise to social justice movements and activists such as the anti-diet movement, fat activists, Health at Every Size, and anti-diet culture advocates (James, 2020). Regardless of age, the study's participants became social and cultural critics, which parallels what other researchers have found to be an important part of the recovery process (Allison et al., 2021).

Third, diet culture overlays psychospiritual health because of what it means to the study's participants—a system that promotes unhealthful beliefs and values that feel like AN and capable of feeling both threatening and motivating to recovery. For some, recovery includes actively parsing out and moving away from cultural definitions of health and re-defining health. Part of this redefining involves learning and unlearning. The experience of diet culture perpetuating harmful beliefs about nutrition and physical activity is not novel (National Institute of Diabetes and Digestive and Kidney Diseases, 2017). Not only were participants battling intrusive thoughts about self, food, and body image during AN, now they battle societal standards of “health” during recovery. As a result of believing limiting beliefs about their worth based on their physical appearance, some expressed feelings of shame and worthlessness. Since diet culture reinforces an obsession with their physical state of being, it logically follows that their recovery experience includes elevating other aspects of health. For most, learning about diet culture empowers them in their recovery because it allows them to clearly differentiate what is healthy and what is not. While the study's participants share similar values around healthy eating

and intuitive body movement, health is more than their physical state of being. For them, health includes emotional/mental, relational, and spiritual aspects.

For the study's participants, the experience of diet culture overlaps with their identity—either as women, mothers, partners, daughters, therapists, and/or friends. For most, diet culture was part of their illness experience, which is why the process of separating from it in recovery is integral. For some, diet culture is experienced very differently in their intimate relationships, giving rise to some strong emotions. Some of their experiences (e.g., vulnerability for others, feeling angry, misunderstood) activate them toward creating positive change in their environments. Despite strong emotions about diet culture, the appeal of diet culture to tie physical health choices to morality/self-righteousness and a sense of control was not lost on the participants. As these findings suggest, the process of externalizing from diet culture is an ongoing and active fight.

For some participants, their experience of diet culture fuels their recovery because they feel compelled to speak up and educate others on how diet culture is oppressive (Harrison, 2018). Negative energy is channeled into purpose and social activism. In fact, one study recently demonstrated how diet culture is informed by feminist, fat activist, and health professional perspectives to challenge myths and misconceptions about dieting and health (Jovanovski & Jaeger, 2022). These researchers argue that dieting has been a contemporary women's health issue for over five decades and has been reinforced by harmful cultural values around food and women's bodies (Jovanovski & Jaeger, 2022). It is important to note the unique experience of oppression as it relates to the social locations within this sample (i.e., White, cisgender women). Although white bodies are not societally marginalized, female bodies are through objectification (Kellie et al., 2019). Although this study's sample was centered on White individuals, their

experience of AN and recovering from AN point to a larger systemic problem (i.e., skewed *DSM-5* criteria [APA, 2013] and societal assumption that AN impacts only thin body types).

Since recovering from AN was compared to recovering from an addiction, which has been previously voiced by others in recovery (Conti, 2018), applying an addiction framework to their experience of diet culture is not far-reaching. Different from a drug addiction, their triggers (e.g., food, fad diets, physical fitness programs) cannot be avoided and are culturally acceptable. Therefore, diet culture may increase their vulnerability to relapse because they are constantly faced with triggers, including food, eating, and weight/body talk in their social contexts.

Given their experience of diet culture feels like their experience of AN, diet culture has the potential to threaten their sense of freedom/separation from AN. Similar to the battle metaphor and constant fight which has been described by individuals in recovery from AN elsewhere (Conti, 2018), it makes sense that some participants feel incited to fight and reject this system. In sum, their relationship to diet culture feels like their relationship to AN—a conscious awareness they live with every day—but slightly different from AN because this relationship has the capacity to motivate them onward in recovery.

### **Strengths and Limitations**

The findings from this current study should be considered in light of its strengths and limitations. There are two major strengths that highlight the importance of this research contribution. First, this was the first phenomenological study of diet culture for individuals in recovery from AN. Phenomenology is a valuable and important approach for new research because it provides a deep understanding of a shared experience for a group of people (Creswell & Poth, 2018). The information learned from this study uniquely contributes because it underscores the role of diet culture, a shared sociocultural experience, in the lives of those in

recovery from AN. Second, despite a small sample size, there was a diverse age range and broad recovery experiences.

Research is not without limitations. There are two main limitations to the research that need to be acknowledged as the results are considered. First, the majority of participants were White, non-Hispanic, cisgender and partnered women, indicating low diversity across social locations. Although prevalence rates differ, AN is not limited to certain demographics, but spans all racial and ethnic groups, gender identities, and socioeconomic statuses (National Institute of Mental Health, 2017). Lastly, although much can be gleaned from eight participants, these findings should be applied cautiously because they do not generalize to the rest of the population. While generalization of results is not the purpose of phenomenological work, it is still important to note this limitation. In light of the findings and limitations, implications for clinicians and future research will be addressed.

### **Clinical Implications**

Healthcare providers (e.g., medical family therapists, physicians, psychologists) need to recognize the role of diet culture in recovery and be mindful of how healthcare encounters can be triggering for individuals in recovery from AN. There are seven practical ways to navigate these encounters and support the overall health and well-being of individuals in recover:

(1) Waiting rooms need to have a variety of literature that is non-food or weight/body-focused and scales should be used with medical discernment. For example, travel, auto, or home décor magazines contain less triggering content and could help reduce the level of anxiety experienced in medical offices.

(2) If not medically necessary, then weight does not need to be measured. However, since weight is a vital sign and sometimes necessary, it is recommended to provide the choice for

patients to either turn around or hide the value. One participant noted that using a different metric system on the scale surprisingly helped reduce her anxiety (e.g., kilograms instead of pounds).

(3) Medical staff (e.g., providers, clinic staff, etc.) should avoid using evaluative comments about food choices or weight (e.g., good vs. bad, unhealthy vs. healthy) and use neutral and unbiased language instead by discussing the function of food and stating observations or facts about weight changes. Do not assume that a healthy body mass index or normal labs indicate well-being or health as one participant specifically noted. This is important for individuals in recovery because complimenting their healthy eating (e.g., cutting out “junk” food) may solidify disordered eating patterns (i.e., orthorexic tendencies). Body and weight concerns may be an issue during recovery as they try to stay within a healthy weight range or maintain their weight (Beilharz et al., 2019), and since weight gain is a sign of health for individuals with a history of AN, comments praising low or normal weight or encouraging more physical activity may contribute to feelings of body dysmorphia or affirm maladaptive beliefs and behaviors (e.g., overexercising).

(4) Discourage dieting, promote moderation and balance with food choices and physical activity. As the participants expressed, overall health means unlearning food rules, addressing food fears/avoidance, learning about the function of food within the body, listening to their bodies, practicing flexibility with food choices, and intuitive eating.

(5) Shift the focus from food and weight when appropriate and engage patients in conversations outside of their physical health (e.g., mental/emotional, relational, spiritual well-being). The participants in the current study stressed the importance of every aspect of their health to support their recovery process. Not only has an overemphasis on food and weight (in

treatment settings) been voiced by other women in recovery, but also a desire to be treated and seen as whole (Rance et al., 2017).

(6) Healthcare providers are also encouraged to be aware of their own beliefs, biases, and assumptions regarding food choices, dietary practices, and body sizes/types. According to this study's participants, unchecked assumptions or biases can lead to unawareness or ignorance of the impact of internalized beliefs on others and result in negative interpersonal relations, which may also be applied to the patient-provider alliance (e.g., feeling misunderstood, frustrated, or alienated).

(7) Healthcare providers are encouraged to assess family dynamics in relation to food choices, eating behaviors, and physical activity and create family-level goals that promote healthy communication skills, reduce parent or caregiver blocks (e.g., fears and self-blame), and increase positive emotional experiences. Previous researchers have shown that skills-based interventions for parents or caregivers not only reduce high expressed emotion (e.g., hostility, criticism, and emotional overinvolvement; Philip et al., 2020), increase parental involvement in recovery and reduce negative emotion blocks (e.g., self-blame, fears; Lafrance Robinson et al., 2016), and improve communication and coping skills (Treasure et al., 2015), but also improve patient outcomes. These studies demonstrate how improving family functioning reduces symptomatology, implying a systemic and relational orientation facilitates recovery.

### **Implications for Future Research**

In light of the limitations of the current study, there are some recommendations for future research. Due to the lack of diversity and small sample size in this current study, future studies should aim to use larger scale recruitment methods (e.g., Listservs, community-based) to recruit participants from diverse social location backgrounds. For example, studies should examine the

role of diet culture among different racial and ethnic groups such as non-White groups and Hispanic/Latinx population since body type ideals differ across these groups (Rodgers et al., 2018). Studies should also explore the experience of diet culture across sex or gender identity (e.g., males, non-binary, and gender fluid) since disordered eating is becoming more recognized and prevalent among these groups (Diemer et al., 2015; Weltzin et al., 2012). While this study examined individual experiences, future studies should examine multiple perspectives on the role of diet culture within dyadic and family systems. Dyadic and systemic research is important because family dynamics influence health outcomes (Garris & Weber, 2018) and gaps in family-based treatment studies persist (e.g., social location factors missing, systemic change undermeasured; see Results in Chapter 3). This research could allow for greater understanding of the family culture/environment and intergenerational transmission of diet culture values. Lastly, future studies are recommended to use more quantitative approaches to gain more perspective on a larger, more generalizable scale in order to understand trends.

### **Conclusion**

This current study offers an important contribution to the field of AN and recovery research as the first phenomenological study of diet culture for individuals in recovery from AN. Diet culture shows up in various social contexts—family, social media, healthcare—and is largely experienced as vulnerability because it parallels their experience of AN. Healthcare providers are encouraged to understand the role of diet culture in recovery. Future research is warranted to further understand the role of diet culture within family systems. Overall, the findings highlight that the experience of diet culture in recovery overlays BPSS health and has the potential to be both oppressive and reinforcing of recovery.

**Table 1***Participant Characteristics*

Sample Characteristics	<i>n</i>	Min.	Max.	<i>M</i>	<i>SD</i>
Age at illness onset	7	14	26	20	3.87
Time in recovery (years)	5*	3.5	36	14.3	12.55
Sense of separation from AN	7	2	5	3.86	1.07
Absence of relational conflict around food/eating/body image	7	1	5	2.86	1.77
Internalized Diet Culture Scale (IDCS)	7	26	84	52.14	19.05
Family Assessment Device (FAD)	7	33	42	37.43	3.60

*Note.* Interpreting mean score for IDCS and FAD needs to be done with caution because sample size is low and margin of error is higher with small sample size.

\*Two participants reported being in active recovery in past one to two months due to recent relapse episodes; however, both said their recovery began years ago.

**Table 2**

*Superordinate Themes and Subordinate Themes*

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<b>Superordinate themes</b>	<b>Subordinate themes</b>
1. Vulnerability of Self and Others	
2. Isomorphic to AN	2.1 Control vs. Personal Agency
3. Internalization vs. Externalization	
4. Intense Emotional Experiences	4.1 Social and Family Culture
5. Redefining Health	

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## CHAPTER 6: A PATH TOWARD HEALING FOR INDIVIDUALS AND FAMILIES WITH OR IN RECOVERY FROM ANOREXIA NERVOSA

Eating disorders are steadily increasing on a global scale (Galmiche et al., 2019) and nearly 28.8 million people alive in the United States in 2018-19 will have an eating disorder at some point during their life (Deloitte Access Economics, 2020). Anorexia nervosa (AN) is the most life threatening of all eating disorders with a mortality rate six times higher than healthy peers (Fichter & Quadflieg, 2016), and one of the highest suicide risk rates of all mental health disorders, second only to opioid addiction (Chesney et al., 2014). Risk of relapse is particularly high within the first year following treatment (Khalsa et al., 2017) and recent evidence suggests that only a minority of patients with AN may fully recover (Franko et al., 2018). AN is no discriminator—it crosses all social locations (i.e., ages, gender identities, sexual orientation, races, ethnicities, socioeconomic status, and body sizes; National Institute of Mental Health, 2017) and impacts every aspect of health (i.e., biological/physical, mental/emotional, social, and spiritual [BPSS]).

### **Dissertation in Review**

The purpose of this dissertation was to address gaps in relationally oriented treatment studies and recovery research for individuals and their families with AN. Each chapter of this dissertation provides context and unique contributions to the understanding of relationally oriented treatment studies and recovery from AN. In chapter one, an overview of the evolution of AN as a diagnosis and history of family and couple-based treatments was provided to set the foundation for the following chapters. Over the past 30 years, AN has evolved into a complex and systemic diagnosis to underscore the multifactorial biopsychosocial (BPS) factors (Culbert et al., 2015). Treatment for AN was originally developed by family therapists (Dare, 1985;

Minuchin et al., 1975), and despite the innovation of other effective treatment models, family-based treatments (FBTs) continue to rank as one of the most effective interventions for adolescent AN (Lock, 2019). Despite research and treatment for AN progressing in the 21<sup>st</sup> century, gaps in family-based interventions and prevention science still exist (e.g., high rate of relapse and rising prevalence of eating disorders; Galmiche et al., 2019; Khalsa et al., 2017). In order to fully understand an illness and how best to treat or prevent it, there needs to be a full understanding of it.

Therefore, chapter two delved into the literature on biological precursors of AN, physical symptoms, psychological risk factors and symptoms, social risk factors and symptoms, and spiritual symptoms or outcomes. Social risk factors included sociocultural (e.g., social media and diet culture) and relational (e.g., family environment). While the BPS etiological model informs the pathogenesis of AN and treatment approaches, the biopsychosocial-spiritual (BPSS; Engel, 1977, 1980; Wright et al., 1996) framework provides a more holistic and systemic approach to understanding symptom maintenance, treatment, and recovery. This in-depth literature review highlighted AN as a whole health illness and underscored the multisystemic and interactional dynamics that require holistic treatment.

Next, chapter three was a systematic review of relationally oriented treatments (couple and FBTs) for AN to understand how they address BPSS health through a dyadic/family systems lens. Chapter four provided the methodological basis for the original research study which was a mixed methods design of quantitative and qualitative approaches (i.e., descriptive statistics and interpretative phenomenological analysis). Chapter five was the original research which included in-depth interviews with eight participants in recovery from AN and their lived experience of diet culture. Findings from chapters three and five are summarized in the next section. The

current chapter (i.e., Chapter 6) discusses a summary of the dissertation as a whole and provides informational documents—based on the findings from this dissertation—for providers to give to families experiencing AN.

### **Conclusion of Major Findings**

Summarized in this section are the main findings from the systematic review (i.e., Chapter 3) and original research study (i.e., Chapter 5) because they offer unique contributions to the field of AN—from treatment to recovery. The systematic review yielded 3,183 studies (duplicates removed), and after the first and second round of screenings were completed, a total of 20 FBT studies were included in the final analysis, absent couple-based treatment studies. The major findings from the review demonstrated that measuring all aspects of health in terms of FBT outcomes lags. Some aspects of health (e.g., relational and spiritual) continue to be overlooked while others (e.g., physical and psychological) were elevated in FBTs for AN. Moreover, dyadic/family outcomes were underreported (60% of studies) and social location factors for all family members included in treatment were missing. The main take-away was that a relational and systemic orientation was inconsistently apparent from data collection to outcomes in FBT studies. Chapter five demonstrated that the experience of diet culture in recovery overlays BPSS health, including relational dynamics (e.g., conflict as it relates to food/eating/body), and has the potential to be both oppressive and reinforcing of their recovery. The findings from these studies corroborate decades of research highlighting the undisputed role of the family in treatment and recovery from AN and contribute to the field of AN by demonstrating the necessity of integrating physical, psychological, social, and spiritual health factors to facilitate positive change toward recovery. The role of the healthcare provider to apply

a systemic and relational orientation when working with individuals or families with AN is provided below.

### **Role of Healthcare Provider**

Healthcare providers (e.g., medical family therapists, physicians, professional counselors, marriage and family therapists, nurses, psychologists, etc.) in a variety of clinical settings (e.g., primary or specialty care settings) will encounter individuals and/or families with AN or in recovery from AN. It is recommended that providers, specifically non-eating disorder providers, not hinge on *DSM-5* criteria (APA, 2013) to assess or treat AN. Rather, it is important that providers have knowledge in assessing and treating the *whole person* by understanding the BPSS illness experience of AN, including relational (e.g., loss of interpersonal connection) and spiritual (e.g., loss of identity) experiences. Moreover, it is important that providers understand how diet culture is experienced in recovery—how it overlays relational dynamics and has the capacity to be both threatening and motivating to recovery. Therefore, healthcare providers are encouraged to use the following resources in their clinical practice:

(1) *Clinical Interview for Healthcare Providers* is a handout (see Figure 1) that can be used to systemically assess patients' overall health in relation to food, eating behaviors, and body image. These assessment questions are appropriate for new patients and returning patients as an ongoing assessment. Not only will they add more contextual understanding to a *DSM-5* diagnosis (APA, 2013), but also help prioritize treatment goals. The interview questions are not exhaustive and clinicians are encouraged to add their own follow-ups. Clinicians are commended to practice ethically and consider the limits of their scope of practice. If a patient is in an active eating disorder or relapsing, then it is recommended to refer the patient to specialized care.

(2) *Whole Health Interventions for Clinicians* is a “cheat sheet” of interventions (see Figure 2) which providers can utilize in their practice to aid in developing treatment goals. The interventions were informed by clinical models (e.g., cognitive-behavioral therapy, dialectical behavioral therapy), but can fit with diverse clinical approaches/orientations.

(3) *‘Dos and Don’ts’* is a handout (see Figure 3) that healthcare providers are recommended to share with families or support persons they treat to help them provide support to and mitigate risk of relapse for their loved ones. It is important to note that this document is not an exhaustive list and should be utilized as a starting point for discussions with families. Additionally, the document assumes a level of familial safety and healthcare providers are recommended to use discretion when or if it is appropriate to distribute and/or utilize.

(4) *Resources* is a handout (see Figure 4) specifically for families with loved ones in recovery from AN. Organizations with mental health support, family therapy, and eating disorder and recovery support groups are provided. Recommended books for families to learn about diet culture, anti-diet culture movements such as Health at Every Size, and intuitive eating are also provided.

## **Conclusion**

Although AN is a well-studied illness, healthcare providers are continuing to learn about it. FBTs are first line of defense for treating AN, but FBT studies skew toward weight and eating disorder pathology to measure change. While physical health is important, recovering from AN is more than refeeding or weight stabilization. Healthcare providers need to know how to engage the *whole person* with AN and address the challenges associated with recovery such as diet culture. This dissertation helped shed light on some of the gaps that exist in FBT studies and recovery research for AN.

**Figure 1**

*Clinical Interview for Healthcare Providers*

# Clinical Interview for Healthcare Providers

## **Physical:**

- Have you noticed any changes in your physical health lately?
  - Which ones concern you the most?
- Have you tried to change your weight or body shape/size recently?
  - If so, what have you tried?
- What do you notice in your body when you feel an emotion like anger, anxiety, sadness, etc.?
  - What makes these emotional experiences better or worse?
  - What role does food or exercise play in how you deal with negative emotions?

## **Psychological:**

- Do you ever feel pressure to look a certain way?
  - Where does this pressure come from?
- Is there a time period in your life where you felt your relationship with food started to shift?
  - What was different then?
- How is your thought process before, during, and after eating?
- How often do you think about food, eating, or your body size/weight?
  - How often and for how long do you exercise?

## **Social:**

- Have you noticed any changes in your relationships with your friends and family due to your eating habits or behaviors?
- How do peers, coaches and/or teachers influence your body image?
  - How do they influence what you eat and how much you exercise?
- How does social media influence how you feel about your body?
  - How does it influence what you eat and how much you exercise?
- How much do you compare yourself in terms of your body size/weight and food choices to those around you?
- Where do you learn about healthy eating and exercise?

## **Spiritual:**

- What beliefs about food and your body feel oppressive to you and which ones feel liberating?
  - How do these beliefs impact your eating, food choices, and body image?
- What would you like to change about how you view yourself in terms of your body image?
  - What does a positive body image look like?
- What do you value about your life or hope to value more?

*Note.* These are assessment questions only, not diagnostic. While they can be used in addition to a *DSM-5* diagnosis (APA, 2013), they should not replace a clinical diagnosis.

Written by Evie DavyRomano (2022)

**Figure 2**

*Whole Health Interventions for Clinicians*



**Physical/Experiential**

- Practice mindfulness
- Explore grounding techniques to use before and after mealtime
- Encourage body movement through gentle approaches (e.g., yoga or stretching)
- Encourage creative expression (e.g., paint, draw, write poetry)
- Practice diaphragmatic breathing for anxiety management

**Psychological**

- Reduce vulnerability to negative emotions (e.g., cognitive reframing)
- Teach distress tolerance skills
- Address negative thinking traps (e.g., catastrophizing, all-or-nothing thinking, etc.)
- Practice scaling anxiety/distress before and after eating
- Address & validate eating/body concerns
- Do exposure work with food fears

**Social**

- Teach assertive communication skills & conflict resolution skills
- Invite family or support persons in to discuss ways to show practical and emotional support
- Explore ways to (re)connect with friends and deepen meaningful relationships
- Discuss value in joining support groups outside of individual and/or family therapy (online or in-person)

**Spiritual**

- Explore values in life
- Discuss role of prayer and/or meditation
- Use self-compassion journal exercises
- Encourage activities that increase inner peace and overall well-being (e.g., nature walks, listening to music, self-care days)
- Address maladaptive beliefs and values about identity and food/eating/body image

Written by Evie DavyRomano (2022)

**Figure 3**

*Do's and Don'ts for Families in Recovery from Anorexia Nervosa*

Do's and Don'ts for Families in Recovery from Anorexia Nervosa

Include a variety of food groups in your diet (e.g., fruits, vegetables, grains, proteins, fat, dairy)	Don't cut out food groups, avoid certain foods <sup>1</sup> , or follow fad diets (e.g., Paleo, Keto, Whole 30, vegan, clean eating, gluten free, low carb or low fat, etc.)
Learn the function of food to counter faulty food beliefs (e.g., "Carbs are bad") and discuss food in a neutral way (e.g., carrots support eye health or peanut butter is a source of fat and protein)	Don't label foods as "bad" or "good"
Eat balanced meals at regular times during the day and encourage family meals as often as possible	Don't skip meals or eat less during one meal to compensate for a bigger meal later
Keep mealtime conversations non-food focused and positive (e.g., play conversation table games)	Don't bring up triggering topics during mealtime (e.g., exercise habits, ongoing contentious issues) or critique the food/meal (i.e., good/bad, worst/best)
Model positive body image by naming gratitude for your body (e.g., able to walk, travel, hug/see loved ones)	Don't make negative comments about your own body image in front of loved one
Practice gentle body movement (e.g., yoga, walking, dancing, etc.) and invite loved one to join when they feel ready	Don't make comments about exercising as punishment (e.g., "I need to walk off that dinner")
Learn how to eat mindfully and intuitively with a balance of processed and unprocessed foods (e.g., packaged, meat, and plant-based)	Don't assume food avoidance of less healthier options (e.g., processed/refined foods) is healthy for your loved one (e.g., obsession with healthy eating is another eating disorder—orthorexia)
Challenge weight stigma in yourself or other family members and accept that health comes in every size and shape	Don't deny how biases can influence not only your own body image and behaviors but also your loved one's body image
Seek to understand how your food choices, eating behaviors, and physical activity are experienced by your loved one in recovery and be willing to make changes as needed (e.g., "What do you wish were different about my relationship to food or exercise?")	Don't dismiss their experience by reacting in self-defense because it doesn't match your experience or your intentions
Invite all emotions into exchanges with loved one (e.g., anger, disappointment) and seek to understand your own emotional responses when it comes to addressing fears or concerns within your family <sup>2,3</sup>	Don't allow self-blame or fear to block your understanding of their experience or discourage expression of negative feelings, especially if they are directed at you
Respect your loved one's recovery process and learn about their ongoing struggles (e.g., "What makes recovery more or less challenging?"; "When do you feel most triggered or at risk of relapse?"; "How do I play into those triggers?") <sup>3</sup>	Don't assume their eating disorder was only about food/body/weight concerns or that their struggles are over once they weight restored or completed treatment
Honor all aspects of your loved one's health (i.e., physical, mental/emotional, relational, and spiritual) and find ways they can grow beyond their physical health	Don't overvalue the body by overdoing exercise or using food or dietary restriction as means for self-improvement (e.g., intermittent fasting, sugar free, detoxes/cleanses, strict fitness programs)
Communicate your support (e.g., "What do you want my role to be in your recovery?"; "What can I do to support you in your recovery today or this week?"; "What do you need from me?")	Don't underestimate your role in your loved one's recovery

Note. These are not one-size-fits-all suggestions. They can be used across the recovery trajectory and adapted to fit your loved one's stage of recovery.

<sup>1</sup>Unless adhering to religious tradition (e.g., fasting and/or a food group needs to be avoided [e.g., pork, beef]) or food allergy is present. If appropriate, consider alternative, non-food abstention practices.

<sup>2</sup>Putting boundaries on hurtful expressions of negative emotions are recommended (e.g., yelling or physical outbursts are not permitted).

<sup>3</sup>Seeking professional help is recommended to learn how to communicate more effectively and manage your own emotional experiences and expectations.

Written by Evie DavyRomano (2022)

**Figure 4**

*Resources for Families in Recovery*

Resources for Families in Recovery from Anorexia Nervosa

Organization	Website
National Association of Anorexia Nervosa and Associated Disorders (ANAD)	<a href="https://anad.org/get-help/eating-disorders-helpline/">https://anad.org/get-help/eating-disorders-helpline/</a>
National Eating Disorders Association (NEDA)	<a href="https://www.nationaleatingdisorders.org/parent-toolkit">https://www.nationaleatingdisorders.org/parent-toolkit</a>
Recovery Warriors	<a href="https://recoverywarriors.com/">https://recoverywarriors.com/</a>
American Association for Marriage and Family Therapists (AAMFT)	<a href="https://www.aamft.org/Directories/Find_a_Therapist.aspx">https://www.aamft.org/Directories/Find_a_Therapist.aspx</a>
Mental Health Professionals Directory	<a href="https://www.psychologytoday.com/us/therapists">https://www.psychologytoday.com/us/therapists</a>
Recommended Reads	
Anti-Diet: Reclaim Your Time, Money, Well-Being, and Happiness Through Intuitive Eating by Christy Harrison, MPH, RD	
Intuitive Eating: A Revolutionary Anti-Diet Approach by Evelyn Tribole, MS, RDN and Elyse Resch, MS, RDN	
Body Respect: What Conventional Health Books Get Wrong, Leave Out, and Just Plain Fail to Understand about Weight by Lindo Bacon, PhD (formerly Linda Bacon)	
The Body Is Not an Apology: The Power of Radical Self-Love by Sonya Renee Taylor	
Health At Every Size by Lindo Bacon, PhD (formerly Linda Bacon)	

*Note.* HAES (Health At Every Size) is a movement occupied by both individuals in recovery from eating disorders and fat activists and fat liberationists. HAES and anti-diet culture movement have been helpful for some, but not for all (e.g., read *The Unbearable Whiteness and Fatphobia of “Anti-Diet” Dietitians* by Marquisele Mercedes).  
 Provided by Evie DavyRomano (2022)

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# APPENDIX A: IRB APPROVALS



**EAST CAROLINA UNIVERSITY**  
**University & Medical Center Institutional Review Board**  
4N-64 Brody Medical Sciences Building · Mail Stop 682  
600 Moye Boulevard · Greenville, NC 27834  
Office 252-744-2914 · Fax 252-744-2284  
[rede.ecu.edu/umcirb/](http://rede.ecu.edu/umcirb/)

## Notification of Initial Approval: Expedited

From: Social/Behavioral IRB  
To: [Evie Davyromano](#)  
CC: [Katharine Didericksen](#)  
Date: 4/1/2021  
Re: [UMCIRB 21-000574](#)  
Lived Experience of Diet Culture

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) occurred on 4/1/2021. The research study is eligible for review under expedited category # 6, 7. The Chairperson (or designee) deemed this study no more than minimal risk.

As the Principal Investigator you are explicitly responsible for the conduct of all aspects of this study and must adhere to all reporting requirements for the study. Your responsibilities include but are not limited to:

1. Ensuring changes to the approved research (including the UMCIRB approved consent document) are initiated only after UMCIRB review and approval except when necessary to eliminate an apparent immediate hazard to the participant. All changes (e.g. a change in procedure, number of participants, personnel, study locations, new recruitment materials, study instruments, etc.) must be prospectively reviewed and approved by the UMCIRB before they are implemented;
2. Where informed consent has not been waived by the UMCIRB, ensuring that only valid versions of the UMCIRB approved, date-stamped informed consent document(s) are used for obtaining informed consent (consent documents with the IRB approval date stamp are found under the Documents tab in the ePIRATE study workspace);
3. Promptly reporting to the UMCIRB all unanticipated problems involving risks to participants and others;
4. Submission of a final report application to the UMCIRB prior to the expected end date provided in the IRB application in order to document human research activity has ended and to provide a timepoint in which to base document retention; and
5. Submission of an amendment to extend the expected end date if the study is not expected to be completed by that date. The amendment should be submitted 30 days prior to the UMCIRB approved expected end date or as soon as the Investigator is aware that the study will not be completed by that date.

The approval includes the following items:

Name	Description
Definition of Diet Culture	Additional Items
Demographics and Diet Culture Internalization Survey	Data Collection Sheet
Informed Consent	Consent Forms
Interview Guide	Interview/Focus Group Scripts/Questions
Recruitment Email	Recruitment Documents/Scripts
Recruitment Protocol	Recruitment Documents/Scripts
Resources	Additional Items

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.



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**Notification of Amendment Approval**

From: Social/Behavioral IRB  
 To: [Evie Davyromano](#)  
 CC: [Katharine Didericksen](#)  
 Date: 10/18/2021  
 Re: [Ame1 UMCIRB 21-000574](#)  
[UMCIRB 21-000574](#)  
 Lived Experience of Diet Culture

Your Amendment has been reviewed and approved using expedited review on 10/18/2021. It was the determination of the UMCIRB Chairperson (or designee) that this revision does not impact the overall risk/benefit ratio of the study and is appropriate for the population and procedures proposed.

Please note that any further changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a Final Report application to the UMCIRB prior to the Expected End Date provided in the IRB application. If the study is not completed by this date, an Amendment will need to be submitted to extend the Expected End Date. The investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Document	Description
Dissertation Proposal(0.01)	Study Protocol or Grant Application
Informed Consent(0.11)	Consent Forms
Interview Guide(0.05)	Interview/Focus Group Scripts/Questions
Recruitment Email(0.03)	Recruitment Documents/Scripts
Recruitment Flyer(0.02)	Recruitment Documents/Scripts
Recruitment Protocol(0.01)	Study Protocol or Grant Application
Survey(0.02)	Surveys and Questionnaires

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

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IRB00000705 East Carolina U IRB #1 (Biomedical) 50RG0000418  
 IRB00003781 East Carolina U IRB #2 (Behavioral/SS) 50RG0000418



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**Notification of Amendment Approval**

From: Social/Behavioral IRB  
 To: [Evie Davyromano](#)  
 CC: [Katharine Didericksen](#)  
 Date: 11/2/2021  
 Re: [Ame2\\_UMCIRB 21-000574](#)  
[UMCIRB 21-000574](#)  
 Lived Experience of Diet Culture

Your Amendment has been reviewed and approved using expedited review on 11/2/2021. It was the determination of the UMCIRB Chairperson (or designee) that this revision does not impact the overall risk/benefit ratio of the study and is appropriate for the population and procedures proposed.

Please note that any further changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a Final Report application to the UMCIRB prior to the Expected End Date provided in the IRB application. If the study is not completed by this date, an Amendment will need to be submitted to extend the Expected End Date. The investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Document	Description
Survey(0.03)	Surveys and Questionnaires

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418  
 IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

## APPENDIX B: SURVEY

Hello!

Thank you for your interest in helping researchers at East Carolina University understand diet culture.

Please download and read the consent form below before proceeding.

The estimated time to complete the survey is 15-30 minutes.

[Informed Consent](#)

**By clicking 'OKAY' you consent to participate in this study.**

(1) By participating in this study, you are confirming the following:

- You are 18+ or older
- Do not have an active eating disorder

(2) Please indicate how much you agree with the following statements:

	Strongly Disagree	Somewhat disagree	Undecided	Somewhat agree	Strongly agree
I feel a sense of separation from anorexia nervosa.	<input type="radio"/>				
My food choices, eating behaviors, and beliefs about my physical appearance do not create conflict in my relationships with friends, family, or partner.	<input type="radio"/>				

(3) Have you ever received a formal diagnosis of anorexia nervosa? If 'yes', please fill in your age when you were first diagnosed.

- No
- Maybe
- Yes

(4) If you answered 'no' or 'maybe', when do you think your eating disorder started (e.g., specific age, age range, and/or period in your life)?

(5) If you answered 'yes' above, have you ever received formal treatment for that diagnosis?

- No
- Yes

(6) How long have you been in recovery from anorexia nervosa? Please specify months or years.

(7) In your own words, how do you define recovery?

(8) Have you ever relapsed?

- No
- I don't know
- Yes

(9) Can you please describe what relapse was for you? If you answered 'no', please type N/A.

(10) If you have not relapsed or don't know if you have, have you ever felt you were at risk for relapse (i.e., returned to eating disorder behaviors, sought treatment)?

- Yes
- I don't know
- No

(11) In your own words, how do you define diet culture?

(12) How much did diet culture contribute to the development of your eating disorder?

- None at all
- A little
- A moderate amount
- A lot
- A great deal

(13) Please indicate how strongly you agree or disagree with each statement.

	Strongly disagree	Somewhat disagree	Undecided	Somewhat agree	Strongly agree
I feel like a lesser person when I see people who appear more physically fit than me.	<input type="radio"/>				
I feel like a lesser person when I eat unhealthy food.	<input type="radio"/>				
I feel ashamed of myself when I am above a certain body weight.	<input type="radio"/>				
I feel guilty when I eat more than I intended.	<input type="radio"/>				
I'm ashamed of myself when I eat certain foods.	<input type="radio"/>				
You can tell a lot about a person's morality by their appearance.	<input type="radio"/>				
An individuals' character is reflected in their food choices.	<input type="radio"/>				

Physically fit individuals are worthier of respect.

Individuals who are physically fit tend to be better people all around.

Individuals who eat healthy have better strength of character. (10)

I try to only eat a specific amount of carbohydrates each day.

I have a specific calorie goal that I always adhere to.

I have strict standards for how much I eat.

I try to only eat a specific amount of protein each day.

I do not count calories or track my food intake in any way.

Individuals should  
strive to obtain an  
ideal body size.

Individuals should  
strive to be  
physically fit.

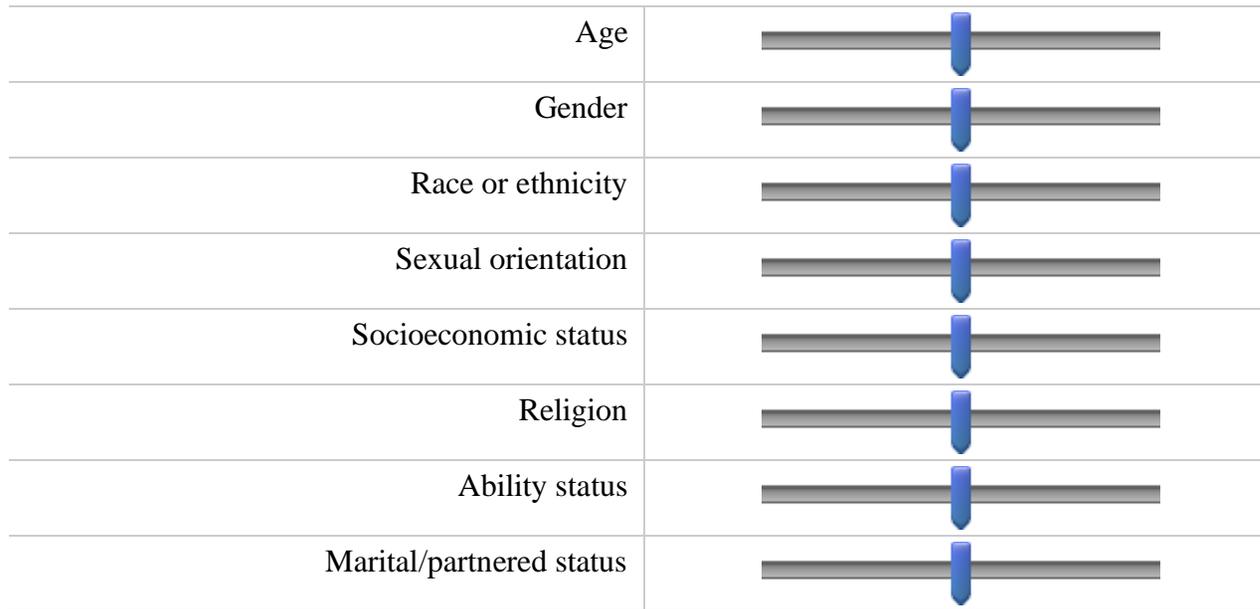
Losing weight is an  
important part of  
becoming healthy.

It is bad to be  
overweight.

Obtaining an ideal  
body size will  
improve an  
individual's quality  
of life.

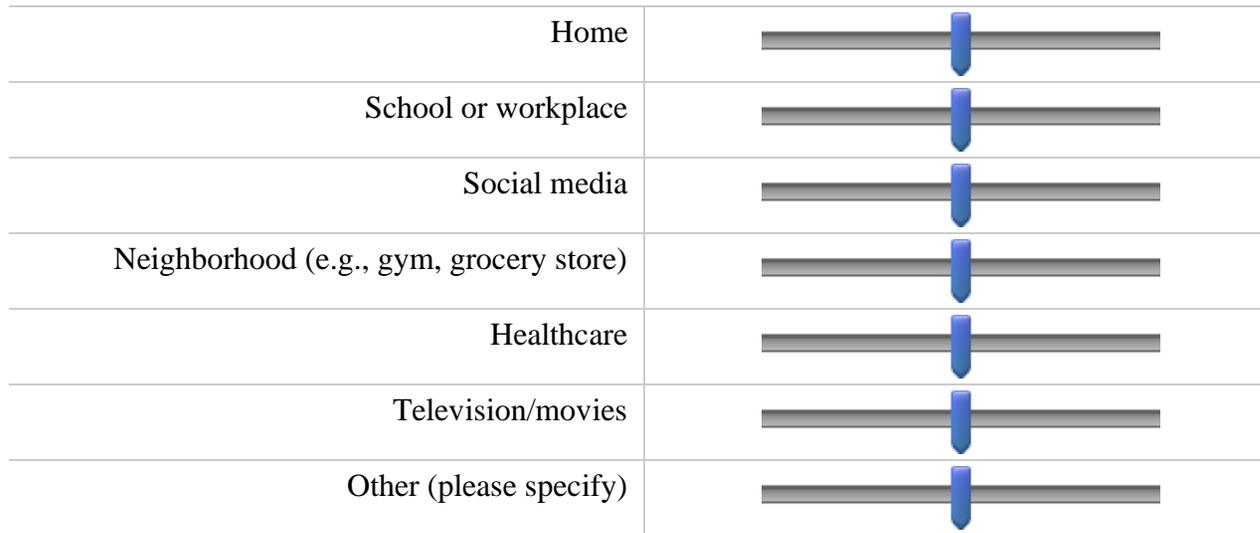
(14) On a scale of 0-10, please indicate the degree to which these aspects of your identity are most impacted by diet culture (0 is not at all impacted or does not apply and 10 is extremely impacted).

0 1 2 3 4 5 6 7 8 9 10



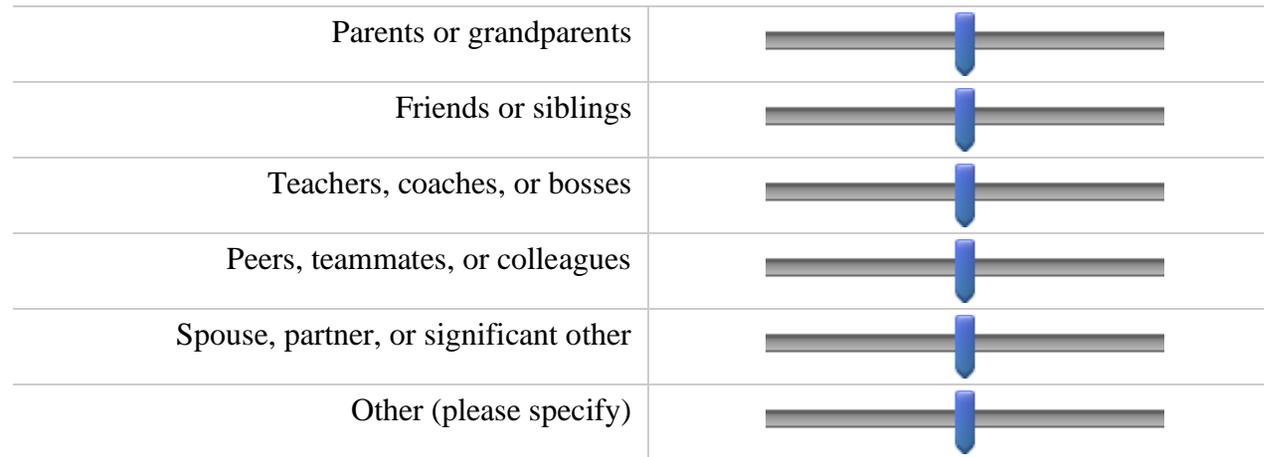
(15) On a scale of 0-10, please indicate the degree to which you observe or encounter diet culture in these environments (0 is not at all observe or encounter or does not apply and 10 is extremely observe or encounter).

0 1 2 3 4 5 6 7 8 9 10



(16) On a scale of 0 to 10, please indicate the degree to which you observe or encounter diet culture within these relationships (0 is not at all observe or encounter or does not apply and 10 is extremely observe or encounter).

0 1 2 3 4 5 6 7 8 9 10



(17) What does diet culture mean to you

(18) Please indicate how strongly you agree or disagree with each statement as it relates to your close immediate family members (e.g., parents, siblings, or grandparents).

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
Planning family activities is difficult because we misunderstand each other	<input type="radio"/>				
In times of crisis we can turn to each other for support	<input type="radio"/>				
We cannot talk to each other about the sadness we feel	<input type="radio"/>				
Individuals are accepted for what they are	<input type="radio"/>				
We avoid discussing our fears and concerns	<input type="radio"/>				
We can express feelings to each other	<input type="radio"/>				
There are lots of bad feelings in our family	<input type="radio"/>				
We feel accepted for what we are	<input type="radio"/>				

Making decisions is a problem for our family

We are able to make decisions about how to solve problems

We don't get along well together

We confide in each other

(19) What is your age?

(20) What is your gender?

- Cisgender man
- Cisgender woman
- Transgender man
- Transgender woman
- Non-binary / third gender
- Prefer not to say
- Other

(21) What is your race?

- White
- American Indian or Alaska Native
- Asian or Asian American
- Black or African American
- Other or mixed race

(22) What is your ethnicity?

- Hispanic or Latino/a
- Not Hispanic or Latino/a

(23) Are you married or in a romantic partnership?

- No
- Yes

(24) What is your current occupation or employment role?

(25) What is your ability status (e.g., physical, intellectual, etc.)? If you identify as able-bodied, you can type none.

(26) Do you currently have other mental health conditions? Please indicate all that apply.

- Generalized Anxiety Disorder
- Major Depressive Disorder
- Obsessive-Compulsive Disorder
- Posttraumatic Stress Disorder
- Other
- None

(27) How can we contact you to schedule your interview?

- E-mail
- Phone call
- Text message
- Other

(28) Please provide contact information (phone, e-mail, etc.):

## APPENDIX C: RECRUITMENT E-MAIL

Hello,

My name is Evie DavyRomano and I'm a medical family therapy PhD candidate at East Carolina University. I do research on recovery from anorexia nervosa, diet culture, and overall health and well-being.

I'm contacting you because diet culture has not been explored from the perspective of individuals in recovery from anorexia nervosa. I believe your experience as an individual recovering from anorexia nervosa (with or without a previous formal diagnosis or treatment) is extremely valuable and would offer a unique contribution to better understanding this sociocultural phenomenon.

With this in mind, I would like to conduct an interview with you in order to understand your experience of diet culture. Prior to the interview, you will be asked to complete an online survey, which is estimated to last between 15 and 30 minutes, and will be completed at your convenience. The interview will be recorded and take place virtually for at least 45 minutes to no more than 90 minutes. You will be eligible to receive a \$20 Amazon gift card for your participation in both the survey and interview. You have the opportunity to agree to opt in or out of this procedure.

If you are interested in participating in this research study or have any additional questions, please feel free to e-mail me at [davyromanoe19@students.ecu.edu](mailto:davyromanoe19@students.ecu.edu).

Thanks for your interest!

Best,  
Evie

APPENDIX D: RECRUITMENT FLYER

## Understanding Diet Culture

Researchers at East Carolina University are looking for individuals who are

**18 years or older** and **recovering from anorexia nervosa\*** to take part in an  
ONLINE STUDY.

The research study will be completed ONLINE (i.e., there is *no* requirement for you to come to the University).

Individuals will be asked to complete an online survey and participate in a one-on-one interview about their experiences with diet culture.

Individuals from diverse backgrounds (e.g., non-White, non-cisgender female) are encouraged to participate

Participants are eligible to receive an Amazon gift card\*\*

\*\*Incentives are for those who complete both the survey and interview

**To find out more or take part in the study, please contact [davyromanoe19@students.ecu.edu](mailto:davyromanoe19@students.ecu.edu)**

*A previous formal diagnosis of and treatment for anorexia nervosa are not required*

\*Anorexia nervosa includes, but is not limited to:

- invasive body/food/eating fears/concerns
- weight loss
- cutting out food groups
- dieting
- fatphobia
- over-exercising
- loss of identity/sense of self, etc.

## APPENDIX E: INFORMED CONSENT



Informed Consent to Participate in Research  
Information to consider before taking part in research that has no more than minimal risk.

**Title of Research Study:** The Lived Experience of Diet Culture for Individuals in Recovery from Anorexia Nervosa

**Principal Investigator:** Evie DavyRomano

**Department:** Department of Human Development and Family Science; College of Health and Human Performance; East Carolina University

**Address:** 610 E 10<sup>th</sup> St, Greenville, NC 27858

**Telephone #:** (678) 323-9878

**Study Coordinator:** Evie DavyRomano

**Telephone #:** (678) 323-9878

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Researchers at East Carolina University (ECU) study issues related to society, health problems, environmental problems, behavior problems and the human condition. To do this, we need the help of volunteers who are willing to take part in research.

### **Why am I being invited to take part in this research?**

The purpose of this research study is to understand the experience of diet culture for individuals in recovery from anorexia nervosa (AN). Diet culture is a sociocultural phenomenon that has not been studied from the perspective of individuals in recovery. You are being invited to take part in this research because of your personal experience as an individual in recovery from AN. The decision to take part in this research is yours to make. By doing this research, we hope to learn how individuals in recovery experience diet culture.

If you volunteer to take part in this research, you will be one of six to twelve persons to do so.

### **Are there reasons I should not take part in this research?**

You should not volunteer for this study if you are (1) under 18 years of age or (2) have an active eating disorder.

### **What other choices do I have if I do not take part in this research?**

You can choose not to participate. If you choose to **not** participate in this research study, the principal investigator, Evie DavyRomano, does not have any other research project options for you to participate in at this time.

**Where is the research going to take place and how long will it last?**

The research will be conducted online and via videoconferencing due to COVID restrictions. First, you will complete an online survey at your convenience and then log on to a virtual meeting platform **one time** during the study. The total amount of time you will be asked to volunteer for this study is **about 1-2 hours**.

**What will I be asked to do?**

You will be asked to do the following: Complete a survey prior to the virtual interview which should take **15-30** minutes and participate in a virtual interview for **45-90 minutes**. You have the opportunity to agree to opt in or out of this procedure.

**What might I experience if I take part in the research?**

We anticipate minimal risks (the chance of harm) associated with this research study. We will be asking you questions about your personal experiences with diet culture while in recovery from AN and understand this can cause some psychological discomfort. We don't know if you will benefit from taking part in this study. There may not be any personal benefit to you, but the information gained by doing this research may help inform prevention and/or treatment practices in the future.

**Will I be paid for taking part in this research?**

We will be able to pay you for the time you volunteer while being in this research study. While there is no limit to how many individuals can complete the survey, only six to twelve individuals will be interviewed. Upon completion of **both** the survey and interview, participants will receive a \$20 Visa gift card. This will be sent to your e-mail as a virtual e-gift card.

**Will it cost me to take part in this research?**

It will not cost you any money to be part of this research study.

Who will know that I took part in this research and learn personal information about me?

ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.

**How will you keep the information you collect about me secure? How long will you keep it?**

Your survey responses and interview, which will be audio/video recorded, will be stored on a secure server that the principal investigator will access through an encrypted and password-protected computer. Only the principal investigator will have access to this information. The audio/video recording will be immediately destroyed upon transcription. The survey responses and transcript will be stored for up to three years and then the files will be deleted. The survey responses and transcript will be for research purposes. The information you provide may be used in future research, and therefore, it will be stripped of any identifiable information and replaced with a numerical identifier and/or alias.

**What if I decide I don't want to continue in this research?**

You can stop participating at any time after the research study has already started. There will be no consequences if you stop, and you will not be criticized. You will not lose any benefits that you normally receive.

**Who should I contact if I have questions?**

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the principal investigator, Evie DavyRomano, at (678) 323-9878 (Monday through Friday, between 8 am – 5 pm).

If you have questions about your rights as someone taking part in research, you may call the University & Medical Center Institutional Review Board (UMCIRB) at phone number 252-744-2914 (Monday through Friday, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director for Human Research Protections, at 252-744-2914.

**Is there anything else I should know?**

Identifiers might be removed from the identifiable private information and, after such removal, the information could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you. However, there still may be a chance that someone could figure out the information is about you.

**If you decide you are willing to take part in this study, click the OKAY button and the survey will begin.**

## APPENDIX F: INTERVIEW GUIDE

Hello!

Thank you for taking the time out of your busy schedule to participate in this interview. I believe your opinions and insights are valuable as an individual in recovery from anorexia nervosa. Your contribution is instrumental to this ongoing work. Some of the following questions are follow-ups and related to the survey you have already completed. Some of these questions may be difficult to answer, so please know that your participation is voluntary and you may refrain from answering a question at any time. Also, everything you share today is confidential. The interview can last from anywhere to 45 to 90 minutes. Before getting into the interview, I'm going to read the definition of diet culture. Diet culture has been defined as "a system of knowledge, values, and meanings that supports interpretations of health choices as moral character, by attaching morality to food choices, eating behaviors, and physical appearance" (Morris, 2020, p. 4).

1. What does this definition mean to you?
2. What are some examples of diet culture's beliefs and values associated with health and wellness?  
Prompt: What do you think or feel about these beliefs and values?
3. Can you tell me more about how diet culture contributed to your diagnosis of anorexia nervosa or behaviors?
4. If it's applicable, can you tell me more about the role diet culture played in your relapse(s) or a season of relapse?
5. Can you tell me about the role diet culture plays in your recovery?
6. What is the main difference between your experience of diet culture now while in recovery and when you were first diagnosed or recognized you had anorexia nervosa?
7. How do you think you would feel about diet culture if you weren't a person in recovery from anorexia nervosa?
8. What role does education or learning play in your recovery as it relates to diet culture?

9. Can you tell me more about diet culture's impact on parts of your identity (e.g., age, race, ethnicity, gender, sexual orientation, ability, married/partnered, socioeconomic status)? Perhaps the ones that experience the most impact?

Prompt: Are there any specific examples or memories that stand out to you?

Prompt: What is it like for you to experience diet culture in this way?

10. Can you tell me more about the contexts in your environment in which you observe or encounter diet culture? Same as above, perhaps the contexts that you encounter it the most?

Prompt: Are there any specific examples or memories that stand out to you?

Prompt: What is it like for you to see diet culture in these contexts?

11. Can you tell me more about the relationships in which you observe or encounter diet culture?

Prompt: Are there any specific examples or memories that stand out to you?

Prompt: What do you think your family or friends think about diet culture?

Prompt: What is it like for you to experience diet culture in these relationships?

12. What does overall health and well-being mean to you?

Prompt: What does it mean for you to be healthy?

13. Is there anything else you would like for me to know?

This concludes the interview. Thank you for your participation and valuable contribution. I am grateful for your time, honesty, and transparency. In case you need additional support, you will be receiving an e-mail immediately following the conclusion of this interview with information on recovery support groups, referral services, and other support services.

## APPENDIX G: LIST OF RESOURCES

Below is a list of resources for you that may be helpful along your recovery journey. Again, thank you for your time and valuable contribution to the field of eating disorders!

The National Eating Disorder Association: <https://www.nationaleatingdisorders.org/>

Referral Sources:

<https://www.edreferral.com/>

Eating Disorders Anonymous:

<http://eatingdisordersanonymous.org/>

Eating Disorder Hope:

<https://www.eatingdisorderhope.com/recovery>

Recovery Warriors:

<https://www.recoverywarriors.com/>

In the case you find yourself experiencing any thoughts of self-harm or suicidal ideation, please don't hesitate to reach out for support. You can call/text the National Suicide Prevention Lifeline at 800-273-8255. They are available 24/7.

