

There may not be one Truth—there may be several truths—but saying that is not to say
that reality doesn't exist.

Margaret Atwood

**SEEING BEYOND THE EATING DISORDER: HEALTH PROFESSIONALS
KNOWLEDGE, SKILLS, AND EXPERIENCES IN EATING DISORDER CARE
IN NEW BRUNSWICK, CANADA**

by

Tanya Lynn Wilson

Bachelor of Social Work, Saint Thomas University, 1992

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Supervisor: Kathryn Weaver, PhD UNB Faculty of Nursing

Supervisory Committee: Mary McKenna, PhD UNB Faculty of Kinesiology

Examining Board: Janine V. Olthuis, PhD UNB Faculty of Arts

Emily Read, PhD UNB Faculty of Nursing

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Dean of Graduate Studies

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ABSTRACT

Health professionals struggle with caring for individuals with eating disorders, especially in New Brunswick, Canada where there is no recognized eating disorder treatment center. Using narrative methodology, this study explored the perceptions, experience, and training of professionals from seven regulated health disciplines that are most commonly involved in eating disorder care— medicine, dentistry, nursing, social work, occupational therapy, dietetics, and psychology. Study results identified two common themes that hinder identification and intervention: the complex nature of eating disorders and the valuing of health priorities within the health care setting. This study brings light to the process professionals go through from seeing beyond the eating disorder to understanding the often subtle subtexts that impede eating disorder identification and treatment. Looking at eating disorder care from an interdisciplinary perspective provides unique insight into common needs and challenges of healthcare providers and may ultimately inform existing and developing treatment and prevention initiatives.

DEDICATION

To the most important people in my world, Richard, Lauren, and Isaac.

Thank you for always being there to support me and for encouraging me to follow my
passion.

I love you beyond measure.

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To my supervisor and mentor, Dr. Kate Weaver, I am forever grateful to you for bringing me on, without hesitation, as a student in your study. Your knowledge of both the subject matter and the methodology was instrumental in guiding my NB study and helping me to understand these complex disorders. Equally importantly, your gentle encouragement to stretch beyond my comfort zone did not go unnoticed and is so very appreciated.

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And lastly, to the dedicated healthcare professionals who participated in this study, my heartfelt appreciation goes out to you. I honor the honesty, passion, and compassion in your stories and recognize the vulnerability that comes with sharing your experiences in a province so small, so that others may learn. My hope is that the findings of this study help to advance eating disorder knowledge and care in New Brunswick.

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Chapter 1. Introduction

Eating disorders, an array of the most complex and life-threatening of all psychiatric illnesses, contribute to the death of between 1,000 and 1,500 Canadians per year (Government of Canada, 2014). At any given point, approximately 600,000 to 990,000 Canadians will meet the diagnostic criteria for eating disorders (Government of Canada, 2014). Although eating disorders—*anorexia nervosa*, *bulimia nervosa*, binge eating disorder, and other specified feeding and eating disorders—each have a specific set of criteria used in diagnosis and treatment for each specific disorder, all are characterized by maladaptive eating patterns and behaviours.

The Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM 5), (2013) defines eating disorders as a “persistent disturbance of eating or eating-related behavior resulting in altered consumption or absorption of food, significantly impairing physical health or psychosocial functioning” (American Psychiatric Association, 2013, p. 329). Eating disorders can affect both genders; however, prevalence is higher among girls and women. Eating disorders typically present in adolescence, and to a lesser degree, in pre-pubertal children (Birmingham & Treasure, 2010) and older adults (Lapid et al., 2010). The prevalence of *anorexia nervosa* among women and girls is 0.3-1% with an onset of mid to late adolescence, while *bulimia* often presents in adolescence or early adulthood and has a female prevalence of between 1-3% (Langlois, Samokhvalov, Rehm, Spence, & Connor Gorber, 2012). *Anorexia nervosa* is the third most common chronic condition in adolescence (Raveneau, Feinstein, Rosen & Fisher, 2014; Trent, Moreria, Colwell & Melher, 2013). Recovery can take between two and seven years and only a

mere 50% will fully recover (Government of Canada, 2014). In addition to serious medical complications, eating disorders have the potential to disrupt normative development in children and young adults, including work, school, and social relationships. According to experts in the field, 15- 20% of individuals affected by anorexia will become treatment-refractory (Government of Canada, 2014). So significant are these marginalized and misunderstood disorders on the health of Canadians that in 2013, the Government of Canada adopted a motion to conduct an in-depth study of eating disorders among girls and women that focused on the availability of treatment and how to facilitate understanding and improve care for those affected. (Government of Canada, 2014). More recently, motion M-117, was presented (42nd Parliament, first session, February 2, 2017) proposing development of a coordinated Canadian strategy on eating disorders. The aim of the proposed strategy is to increase awareness and early detection and improve research and best practice in identification and treatment of eating disorders (Government of Canada, 2017).

Eating disorders are believed to develop from a combination of physiological, psychological, and environmental factors which, in combination, increase the risk for individuals genetically predisposed to developing eating disorders. Although not exhaustive, common risk factors include obsessional childhood traits, susceptibility to cultural and social influences related to athleticism and valuing thinness, brain abnormalities, and family history, especially among first degree relatives (American Psychiatric Association, 2013).

Co-morbid psychiatric disorders are not uncommon. For individuals affected by anorexia nervosa, co-morbidity may include bipolar, depressive, and anxiety disorders as

well as obsessive compulsive disorder and substance use disorder (American Psychiatric Association, 2013). Among individuals affected by bulimia nervosa, frequent co-occurring disorders include bipolar and depressive disorders, as well as increased frequency of mood disturbances, depressive and anxiety symptoms, personality features and disorders, and substance use, particularly stimulant use (American Psychiatric Association, 2013). Comparable to anorexia and bulimia, co-morbidity among those affected by binge eating disorder frequently involves bipolar disorder, depressive disorder, anxiety disorder, and to a lesser degree substance use disorder (American Psychiatric Association, 2013). Additionally, binge eating disorder has been linked to obesity (Austin et al., 2008; Treasure, Claudino & Zucker, 2010).

Early detection and treatment result in positive prognosis for individuals affected by eating disorders. Limited duration or untimely intervention may lead to treatment resistance and chronicity, resulting in potentially avoidable suffering by individuals affected by eating disorders and the loved ones who support them. Diagnosis and treatment requires up-to-date knowledge of best practices in early detection and intervention by health professionals.

Context

Knowledge of eating disorders and the effectiveness of interventions have evolved over time. This is reflected in the changes to the Diagnostic and Statistical Manual of mental disorders (DSM) criteria for eating disorders from 1994 to 2013. Changes include clarification and modification of the diagnoses anorexia nervosa and bulimia nervosa and the removal of the catch-all category eating disorders not otherwise

specified. Important revisions include removal of the criterion of amenorrhea for anorexia nervosa which has implications for males and premenarchal and post-menopausal females, reduction in compensatory behaviors from twice to one time per week for bulimia nervosa disorder, and the addition of binge eating disorder as its own category (American Psychiatric Association, 2013). Changes to the DSM 5 allow for better representation of the symptoms and behaviours of eating disorders (American Psychiatric Association, 2013). Of note, although the term disordered eating is used widely in literature, there does not exist a universally accepted definition, nor is it categorized in the DSM (McIver Mahn & Lordly, 2015). Attention is required to delineate disordered eating from more pervasive behaviours, for example, dieting, common in young women, or occasional episodes of over-eating without the characteristic compensatory behaviours (Shekter-Wolfson et al., 1997).

Current professional practices may reflect outdated perceptions and outmoded interventions, due in large part to inadequate formal education, limited opportunity for ongoing professional development, lack of awareness of referral options, and not enough professional support (Heath et al., 2013). Despite an understanding of the need for solid research and training, gaps continue to exist. For example, research suggests that only half of all individuals affected by anorexia nervosa and only one third of those experiencing bulimia nervosa are ever detected by the health care system (Trent et al., 2013). A corollary of this situation is that health professionals continue to lack the necessary knowledge and skills to effectively screen for and intervene in eating disorder care.

Setting

New Brunswick is one of four Atlantic Provinces situated on the east coast of Canada. New Brunswick is Canada's only officially bilingual province. With a population of approximately 750,000 inhabitants, New Brunswick is characterized by small cities and rural communities. In recent years, New Brunswick's struggle to stabilize its economy has resulted in an out-migration of residents. For citizens who remain, stagnant economic growth has contributed to high levels of labour insecurity, low paying jobs, and higher than average levels of poverty. These demographics add to the challenge of obtaining and providing healthcare for individuals, communities, and government.

New Brunswick is one of the only provinces in Canada without a provincially recognized eating disorder treatment center. Although pockets of expertise exist, approaches to eating disorder care are fragmented. This has implications for both the individuals who require the care and for the health professionals who seek specialized professional guidance and options for treatment. Without a provincial treatment program, it is difficult for professionals to acquire the practical knowledge to intervene on behalf of individuals with eating disorders. Currently, those requiring specialized treatment for eating disorders must travel out of province to obtain care (Kapelos, 2014; Yard, 2016).

New Brunswick Context

The 2010 Status Report published by the New Brunswick Advisory Council on the Status of Women indicates that the number of individuals diagnosed with an eating disorder in New Brunswick mental health clinics by gender, all ages, for the year 2008-2009 was 74 females and 13 males (Johnston, 2010). According to the 2014 provincial

report by the New Brunswick Child and Youth Advocate, the rate of hospitalization for all mental illness in NB exceeded the national rate by almost double, at 64/10,000 compared with Canada at 35.5/10,000 (GNB, 2014).

In Canada, the highest rate of hospitalization for eating disorders occurs in the 10 to 19-year-old age range and the average length of hospital stay for eating disorders is between 31.6 to 33.3 days (CIHI, 2014). According to NB statistics, the rate of hospitalization for eating disorders is 4.3 female to 0.2 male; an over 20 times higher rate of admission by gender (GNB, 2014). Comparatively, 2012-2013 national statistics show a difference between rates of admission based on gender as 15 times higher for females than males (CIHI, 2014). Generally, hospitalization represents the most expensive, and by times, the least effective means of intervention for health issues (GNB, 2015).

Practitioners in New Brunswick require the competence and confidence to identify and effectively intervene within their respective practices. However, as this issue has never been examined in the context of New Brunswick, we have no notion of how helpful current practices are to individuals seeking treatment for eating disorders. Nor do we have a clear understanding of any gaps in knowledge from the perspective of allied health professionals. The absence of strong clinical skill and best practice knowledge can be distressing for both the professional providing the care, and more so for the individual and family who require it.

Purpose of Study

Health professionals struggle with caring for individuals with eating disorders, perhaps even more so in New Brunswick where there is no recognized eating disorder

treatment center. The purpose of this qualitative research was to study the perceptions of health professionals caring for persons with eating disorders in New Brunswick. This research sought to elicit stories of health professionals who care for persons affected by eating disorders. Research findings shed light on the needs of those with eating disorders and the professionals who care for them and provide insight into future potential treatment and research initiatives. Given that New Brunswick lacks a publically-funded eating disorder treatment center, furthering our understanding of the current health care landscape in the province helps bridge the gap between eating disorder knowledge and treatment. These findings may, in turn, contribute to better outcomes for individuals with eating disorders.

Research Questions

Working within a larger Atlantic Provinces study, New Brunswick health professionals were asked to reflect on their experiences, perceptions, and training related to caring for individuals with eating disorders. The purpose of this exploratory research was to elicit the perspectives and experiences of allied health professionals through the following three central questions: 1) What are the stories of allied health professionals who provide services to persons affected by eating disorders? 2) How do allied health professionals conceptualize eating disorders, recovery, and provision of health services? 3) What are the knowledge and practice needs of allied health professionals regarding eating disorder intervention and recovery? To answer these questions, New Brunswick health providers from seven regulated health professions (medicine, nursing, dentistry, occupational therapy, psychology, social work, and dietetics) were invited to share their

experiences in providing treatment and intervention to individuals affected by eating disorders.

Significance of Study

Little is known about the perspectives of Atlantic Canadian health professionals working in eating disorder care. In particular, health professionals' knowledge, skills, and experiences in working with individuals affected by eating disorders has never been studied in New Brunswick. The potential significance of this research project is threefold: 1) results may challenge conventional beliefs about caring for individuals with eating disorders, 2) findings may inform medical and therapeutic approaches to eating disorder care in the province, and 3) findings may influence future health policy directions.

Although particularly salient for New Brunswick, research findings will be of interest to the greater academic and professional health care communities as current research studies examining professional perceptions, knowledge, and treatment of eating disorders from an interdisciplinary approach is very limited. Integrated health care approaches have the potential to improve interdisciplinary collaboration, enhance patient access to services, reduce risk, and ultimately improve quality of care. Therefore, findings may be important in that they may help to inform future interdisciplinary approaches to eating disorder education, treatment, and research. The use of the term "interdisciplinary" in this thesis is meant to indicate integrated approaches to healthcare that reflect collaborative care by multiple health care providers with shared treatment goals. "Inter-professional" is an alternate commonly used term.

Positionality

From a personal perspective, as a young undergraduate social work student, I began to be drawn towards women's issues and consciousness raising. Growing up, I, like most women, struggled with socialization that emphasized physical beauty and desired thinness while simultaneously downplaying non-physical attributes, like intellect or athleticism. In fact, in middle and high school it was considered almost bad form to be comfortable with one's body. Thus, spurring us young women to be self-disparaging in front of peers to garner acceptance. Cultural messages of how to look were everywhere. I vividly recall that as young girls, we would aim to emulate conventional beauty almost forced from the pages of Seventeen, at a much younger age than the subscription title. Fast forward a few decades, and now equally sadly, research suggests that negative body image is no longer limited to girls and women but is becoming increasingly prevalent among boys and men. Today, this culture messaging is adding to distorted self- image and body dissatisfaction for both genders. As such, challenging cultural expectations and promoting healthy body image are important to me, both personally and professionally.

As a licensed allied health professional with experience working both in hospital and community mental health, I have an appreciation of the need for collaborative care, professional skill development, education, and access to adequate patient and family resources for optimal care of patients with mental illness. This is particularly true of eating disorders due to their, at times, intractable nature. As a health practitioner, I am mindful of the inherent challenges of working in a 'system' that emphasizes patient and family centered practice while maintaining hard and fast rules related to kinship, age and transitions, and disjointed approaches within the care continuum. Further, I understand the

constraints of working in a system that espouses professional proficiency without formal opportunities to develop specialized knowledge and with rising pressure to treat chronic disease within the confines of a “system” designed for acute illness.

Research on the social determinants of health shows inequities in access to health care affects health outcomes (McGibbon, 2009). In New Brunswick, this can certainly be said for individuals and families struggling to access care for an eating disorder. Lacking the financial means to access private resources further divides an already marginalized group, adding to the disadvantage for some individuals and their families. To a large extent, public policy determines if, and to what degree, health services are funded. As stewards of health care, health professionals grapple with policy decisions often made at the exclusion of those who are charged with providing the care. Although at times powerless ourselves, health professionals are the public faces of the health system that has the power to enable or impede access to care for those who desperately need it. Health care providers practicing in isolation without clear protocol and adequate professional supports and training are a vulnerable group. To speak out can mean risking alienation by colleagues or raising doubt about professional credentials, either personal or those of peers. Yet, how else can we begin to understand the social, cultural, and institutional contexts in which we work so that improvements can be made? As both a health professional and health researcher in a sparsely populated province, I am acutely aware that many health professionals do not feel empowered to share their story or to voice opposition to systemic injustices. Having had no specialized training in eating disorders, I recall feeling inadequately prepared to provide care to patients affected by eating disorders and their families. There is a need to understand the experiences and

perspectives of health professionals as this knowledge will serve as a catalyst for improved service delivery for individuals requiring intervention for eating disorders in New Brunswick.

Chapter 2. Review of Literature

Introduction

A review of current research on health professionals' perceptions of eating disorders was completed as part of this study. This search was conducted using the search terms "health professional*" OR "doctor" OR "nurse" OR "occupational therapist" OR "psychologist" OR "dentist*" OR "social work*" OR "dietitian" AND "perceive" OR "perspective" OR "attitude" OR "understanding" OR "knowledge" OR "practice" OR "skill" AND "eating disorder*" OR "anorexia" OR "bulimia" OR "binge eating." The primary databases that were searched included PsycInfo, CINAHL, Sociological Abstracts and PubMed up to 2017.

The search strategy involved cutting and pasting the search terms into the respective databases. To be included in the literature review, articles must have met the following criteria: 1) the study reported perceptions, experience, and knowledge of one or more of the represented health professions, 2) the primary research focus was on anorexia nervosa, bulimia nervosa, or binge eating disorder, and 3) mention of eating disorders and health professional(s) separately or together was in the title or the abstract. Articles were excluded if 1) the primary focus did not relate to the above search criteria (for example, if the focus was primarily related to addictions but mentioned eating disorders), 2) the research related to other feeding disorders, 3) the primary focus was on evaluation of a specific intervention or on a subset of the population. In cases where the study included experiences of both patients and health professionals, only those of the professional were considered.

Research articles were largely selected from publications within the past five years to present the latest knowledge of eating disorders. However, due to limited publications in some areas, allowance was made for the inclusion of older articles and position papers, where relevant. Some review articles and books were included as they provided comprehensive overviews of the subject of eating disorders.

Review of current knowledge helps to gauge the gap between New Brunswick clinical context of eating disorder practice and that of the international community and assists with guiding further research. Based on examination of this literature, the following information represents current knowledge about health professionals' perceptions, knowledge, skill, and attitudes related to providing care or services to individuals affected by eating disorders. In this review, the perspectives of dentists and hygienists, dietitians, nurses, medical practitioners, social workers, occupational therapists, and psychologists will be discussed separately and together.

Dentistry

The importance of good oral health and its connection to overall health has led to increased focus on oral-systemic disease paradigms (Clark 2010). Dental problems associated with eating disorders are well documented in literature. Consequently, oral health professionals must view eating disorders as a significant health threat (Clark 2010).

Oral-dental problems can present as early as six months at the onset of eating disorders (Bishop, no date), with varying symptoms depending on type of eating disorder. Signs include dental erosion, caries, tooth sensitivity, and enamel loss (Birmingham &

Treasure, 2010; DeBate, Tedesco & Kerschbaum, 2004). It may also include scarring on hands resulting from the dorsum of the hand striking the teeth during self-induced vomiting, known as Russell's Sign (Birmingham & Treasure, 2010; DeBate, Tedesco & Kerschbaum, 2005; Trent et al., 2013). With proper training, dentists and hygienists are among the first to recognize the signs of eating disorders, and are key to early detection and secondary prevention of illness (DeBate et al., 2006). Yet, there is limited eating disorder research from the perspective of oral health professionals (Clark, 2010). Consequently, the absence of robust research on oral health professionals and eating disorder care has necessitated reliance on expert opinion and case reviews to guide professional practice (Clark 2010).

Despite knowledge of the key role of oral health professionals in early detection, evidence suggests that dentists and dental hygienists lack critical information on the oral and physical manifestations of eating disorders. For example, results of a randomized cross-sectional study of dentists and dental hygienists (N=576) showed low scores related to knowledge of the oral and physical cues of both anorexia nervosa and bulimia nervosa (DeBate, et al., 2005). Results indicated that hygienists showed slightly increased recognition of the signs and symptoms over dentists. According to DeBate et al., (2005), findings are consistent with previous findings that dental professionals are not adequately trained and suggests a need to enhance curriculum and professional development training.

In a further study, DeBate et al., (2006) found that many oral health professionals screen for eating disorders but they are not apt to refer for treatment. These results suggest that either integration between oral and mental health is not yet established, or that oral health professionals are unsure how to bridge dental care with mental health

services. DeBate et al., (2006), concluded there is a low level of readiness among dental hygienists to identify, to provide specific care, or to refer patients with suspected eating disorders. Increased self-efficacy, knowledge of eating disorders, and recognition of these illnesses as a significant health threat increases likelihood of secondary prevention practices (DeBate et al., 2006).

Occupational Therapy

Eating disorders significantly affect activities of daily living (ADLs), such as aspects of self-care and instrumental activities that include leisure, education, and social participation. Through assessment, intervention and evaluation of individuals with eating disorders, occupational therapists can address concerns related to occupational performance in self-care, work, study, and leisure (Canadian Association of Occupational Therapists, no date).

Occupational therapy with individuals experiencing eating disorders involves assessment and intervention related to occupational functioning in the areas of self-care, time management, and stress management (Kloczko & Ikiugu, 2006). A literature search of occupational therapy and eating disorders turned up only one recent publication— a qualitative study that used phenomenological methodology to explore occupational therapists' perceptions of their profession's contribution to work with individuals experiencing eating disorders. The study involved a small sample size (N=3) working in a hospital setting (Kloczko & Ikiugu, 2006). Experience with eating disorder treatment ranged from 2-9 years. Participants identified numerous therapeutic challenges including perceived manipulation by patients, family issues, co-morbidity, and interpersonal

stressors related to school, community, and family. Themes emerged relating to occupational therapists' specific skillset in understanding life roles and the importance in assisting individuals with coping strategies related to these roles. Unique to their profession, participants cited safety issues related to specific occupational therapy interventions, as materials like mineral oil used in therapy with woodworking may be misused, for example, as a laxative. Occupational therapy interventions that were perceived as most beneficial to this patient group include coping skill development, a client centered approach, and emphasis on management of symptoms and activities that encourage self-expression (Kloczko & Ikiugu, 2006). Factors relating to successful intervention were identified as duration of in-patient treatment, and collaboration between team members with development of shared goals (Kloczko & Ikiugu, 2006). Consistent with other research, findings from the occupational therapist study suggests the need for family therapy and an interdisciplinary approach to intervention. Kloczko and Ikiugu further argue the need for more occupational therapist involvement post-discharge, which the authors suggest, falls disproportionately to social workers.

Nursing

Current knowledge related to nursing professionals working in eating disorder care speaks to the importance of a positive nurse-client therapeutic relationship (Murray, Crawford, McKenzie & Murray, 2011; Ryan, Malson, Clarke, Anderson & Kohn, 2006). The life or death nature of eating disorders, particularly anorexia nervosa, adds to the challenge of developing therapeutic rapport, as patient survival often overrides the option to slowly develop therapeutic alliances (Boughtwood & Halse, 2009). Admissions for

eating disorders disrupts and challenges the culture of nursing units (Lowther, 2005). Due to their continual presence in hospital nursing units, nurses are tasked with mediating contentious issues in the absence of other allied health professionals (Raveneau et al., 2014). Further, issues related to enforcing program boundaries with patients can serve to undermine positive nurse-patient therapeutic alliances (Ryan et al., 2006). Coupled with the fact that in-patient admissions are less commonly mental health related, having to intervene on touchy issues may add to the tension and dissatisfaction for nurses providing eating disorder care on general nursing units (Raveneau et al., 2014). However, with appropriate education, training, and interdisciplinary support, research has found that nurses can derive enjoyment from working with this population (Harken, Maxwell, Hainline, Pollack & Roberts, 2017).

Among the identified relational characteristics are empathy, recognition of patients and patient concerns, positive role modeling, acceptance, trust, and clear boundary setting (Bakker et al., 2011; George, 1997; Murray, 2011; Ryan et al., 2006). However, time restraints and work cultures that emphasize addressing physical needs over emotional ones may impede nurses' ability to engage in essential rapport building with patients requiring eating disorder care (Lowther, 2005). Providing needed resources and training to facilitate development of therapeutic rapport is paramount for nurses caring for individuals affected by eating disorders (Ryan et al., 2006).

Reflecting on personal perceptions of body dissatisfaction, not uncommon among those without an eating disorder, was identified as a useful approach to help nurses to relate to patients struggling with eating disorders (Murray et al., 2011). The importance of understanding the psychological profile of the patient with anorexia is a key factor in

avoiding the perception of individuals with the disorder as “difficult” (George, 1997).

Like concerns of manipulation identified by occupational therapists, nurses also struggle with issues of deceit, such as faking voiding or inserting weighted items into body orifices prior to weigh-ins (King & Turner, 2000).

In 2011, a qualitative study involving individual semi-structured interviews with seven nurses and one social worker and one focus group with four nurses, one psychologist, and one dietitian from a Netherlands specialized eating disorder clinic identified four categories relating to nursing care: resumption of normal eating, resumption of healthy exercise habits, development of social skills, and parent counseling (Bakker et al., 2011). Nursing professionals identified that transparency in discussions about maladaptive eating patterns with patients, including challenging secrecy and isolation, was critical to care. In fact, according to participants, clients identified that pressure from the treatment team to eat was pivotal to breaking anorexic eating patterns (Bakker et al., 2011). Nurses also stressed the importance of a gradual transfer of responsibility back to the individual and the development of a relapse plan as vital components of recovery. Challenges related to resumption of healthy exercise included patients’ psychological adjustment to their “new body” once weight gain was restored (Bakker et al., 2011). Consistent with research on occupational therapists working in eating disorder care, nurses also identified the need for patients to develop social skills to facilitate social re-integration.

Dietetics

Medical nutrition intervention is among the core skills in the field of dietetics (Hart et al., 2011). Due to their diverse skill and knowledge in the areas of nutrition, physiology and human development, dietitians are integral to identification and treatment of eating disorders. Yet, dietitians' express dissatisfaction with eating disorder specific training available in Canada. Consequently, dietitians rely on informal learning, interdisciplinary collaboration, and experiential knowledge to guide practice (Cairns & Milne, 2006).

Despite dietitians' roles in caring for individuals with eating disorders and the effect of eating disorders on individual nutritional status, there is limited evidence on effective nutritional interventions. Most studies of dietitians and eating disorder care involve descriptions of clinical practice and lack evaluation of effectiveness (Hart et al., 2011). For instance, contemporary research related to anorexia nervosa suggests that there is no consistent treatment approach or best practice guidelines for re-feeding and weight restoration (Cockfield & Philpot, 2009).

As with other allied health professions, dietitians emphasize the importance of a strong client-professional alliance (Cockfield & Philpot, 2009). A survey of Canadian registered dietitians' educational needs and counselling strategies in eating disorders shows that dietitians work more in an education based role. As such, these professionals are more likely to provide education based intervention over therapeutic behavioural change based interventions, thus highlighting a need for eating disorder specific professional training (Cairns & Milne, 2006). Nutritional expertise is an important component to care for individuals with eating disorders, as contrary to conventional

belief, individuals with eating disorders do not have a good knowledge of nutrition (Cockfield & Philpot, 2009). Therefore, recommended eating disorder intervention includes skill-building related to meal planning, shopping, meal preparation, and portioning— skills that are also endorsed by professional occupational therapists.

Dietitians endorse a collaborative, interdisciplinary treatment team approach to intervention (Hart et al., 2011; Mittnacht & Bulik, 2015). Nutritional approaches are integral to treatment and recovery. Hart et al. (2011) suggest that weak protocols and poor nutrition management may prolong recovery and lead to secondary effects of the disorder. Typically, eating disorder intervention can be managed on an outpatient basis. However, at times, medical instability warrants hospital admission. Weight restoration is not without risks, especially in the initial 7-10 days of re-feeding (Cockfield & Philpot, 2009). A slow approach to prevent refeeding syndrome (Trent et al., 2013), a potentially life-threatening complication related to nutrient deficiencies, is required (Birmingham & Treasure, 2010). The practice of tube feeding is considered a last resort, with other approaches to weight restoration regarded as more favorable options (Cockfield & Philpot, 2009). As there is no clearly identified relationship between sudden death of individuals with anorexia nervosa and age or length of illness (Cockfield & Philpot, 2009), reliance on clinical judgment leaves both practitioner and patient woefully at risk; a risk even more so when one considers the well documented paucity of formal and professional development training in this area. A lack of evidence identifying best practice leaves professionals reliant on clinical judgment (Cockfield & Philpot, 2009) and personal experience (Mittnacht & Bulik, 2015) to guide practice.

Results from a synthesis of eating disorders and disordered eating literature suggest nutrition students and dietitians feel pressure to maintain a certain body weight, show susceptibility to dietary restrictions and weight control, and can be motivated to enter the field based on personal issues related to eating disorders and disordered eating (McIver Mahn & Lordly, 2015). Interestingly, current literature suggests that although research in nutrition and eating disorders refers to “normal eating,” there is nothing in the research to define what constitutes ‘normal’ eating. According to this literature, the concept of normal eating is defined by “‘what it is not’ (i.e., it is not the eating behaviors of eating disordered patients)” (Hart et al., 2011, p. 145). As registered dietitians provide coaching and counselling on healthy eating practices, lack of discipline specific guidance in this regard is perceived as particularly problematic for this health discipline. Further, it is important to consider the tendency of nutrition students and practitioners prone to food restrictions and body weight issues, the heavy reliance on judgment and experience, and an absence of a definition of “normal eating” may impede treatment outcomes. An absence of professional guidelines related to healthy eating adds to the challenge of recognizing maladaptive eating patterns before they become a medical crisis. This highlights the need for ongoing research that considers both what constitutes acceptable norms and disordered patterns of eating.

Social Work

Social workers are integral to treatment for mental health disorders including eating disorders and work as part of the treatment team both within hospitals and in community mental health settings. Social workers have as an important role to obtain the

family perspective on eating disorders. Family therapy is a proven best practice in eating disorder care with youth and adolescents and many family therapists have social work as their disciplinary background (Shekter-Wolfson et al., 1997).

Primary health providers, including social workers, without access to specialist eating disorder programs must possess necessary knowledge and skills as they can be drawn in to direct eating disorder care. In one study on the effectiveness of intensive didactic training for medical social workers practicing in community clinics, social workers completed four intensive training sessions designed to improve knowledge, assessment, and training of eating disorders. Results showed significant improvement in all areas (Gurney & Halmi, 2001). In addition, the study showed that with training, social workers were more likely to screen new patients. However, training did not influence their perceived ability to intervene or the perceived barriers to intervention (Gurney & Halmi, 2001). Further, findings showed that the positive effects of training on social worker knowledge was maintained over a period of six months (Gurney & Halmi, 2001).

Medicine

Primary care, in general, and the role of physicians specifically, are key to early identification and treatment of eating disorders (Green et al., 2008; Gurney & Halmi, 2001; McNicholas, O'Connor, O'Hara & McNamara, 2016). There exists a strong correlation between eating disorder training and comfort level (Banas et al., 2013) yet inadequate formal training persists (Girz, LaFrance Robinson, & Tessier, 2014; McNicholas et al., 2016). Increased knowledge and screening may result in early detection and intervention by physicians (Banas et al., 2013; Bannatyne & Stapleton,

2015; Green et al., 2008; LaFrance Robinson et al., 2013; Linville et al., 2012). Yet medical providers lack the training and confidence to intervene. In a recent study, McNicholas et al. (2016) discovered that a mere 14.9% of respondents felt confident in their ability to manage eating disorders. Similarly, Linville et al. (2010) found that 78% of medical providers were unsure how to treat eating disorders, 92% felt they missed a diagnosis, and 67% endorsed a need for continuing education. Even among psychiatrists, there remains a need for improved education related to diagnosis and treatment of eating disorders (Jones, Saeidi & Morgan, 2013).

While research shows that physicians feel unprepared to provide eating disorder care, how they are trained and what intervention and screening practices are used is less well understood (Linville, Benton & Sturm, 2010). Girz et al. (2014), in examining medical residents' comfort with and knowledge of eating disorders and treatment interventions for children and youth, found that 70% of respondents had less than five hours of eating disorder training. This resulted in feeling inadequately prepared to intervene with this population. Participants were more comfortable with assessment than with treatment of eating disorders. Overall, residents were more comfortable with management and treatment of anorexia nervosa than bulimia nervosa. Residents were least comfortable with subclinical or partial eating disorder presentations that had some symptomology but did not fully meet the criteria for anorexia nervosa, bulimia nervosa, or binge eating disorder. Interestingly, comfort with diagnosis correlated to each successive hour of training and not with year of residency (Girz et al., 2014). Comfort level was significantly higher for paediatric and psychiatry residents than other specialties. Girz et al. concluded that more intense training correlated to increased

comfort with assessment and management of eating disorders. Knowledge of and familiarity with eating disorders, team support, and inter-disciplinary meetings are regarded as helpful for hospital admissions, while impediments to treatment include individualized treatment plans resulting in different rules for different patients, poor communication, and inconsistency among team members (Raveneau et al., 2014).

Health professionals, including physicians, continue to endorse the view that eating disorders are self-inflicted and within a person's control (McNicholas et al., 2016). Green et al., (2008) in exploring how beliefs and attitudes influence physicians' referral behavior found that despite clear national guidelines, much of the variation in participant referral patterns was attributable to subjective attitudes rather than best practice or actual norms. Further, medical attitudes endorsing poor prognosis and chronicity of eating disorders persist (Currin, Waller & Schmidt, 2009; McNicholas et al., 2016). Although McNicholas et al. (2016) found psychiatrists to be most knowledgeable about eating disorders, they were also most pessimistic about prognosis, which was ascribed to exposure to patients who are most ill.

Misconceptions, for example endorsing the view that patients with anorexia typically look underweight, may lead to delayed treatment or a failure to identify eating disorders (Currin et al., 2009). Since the presenting problem is frequently more physical in nature, practitioners must pro-actively screen for eating disorders (Birmingham & Treasure, 2010; Trent et al., 2013). Yet in their study, Linville et al. (2012) found that almost 60% of primary practitioners did not flag an eating disorder when patient weight was within normal range. Although the SCOFF questionnaire is often used as a screening tool by physicians to detect eating disorders (Birmingham & Treasure, 2010; Trent et al.,

2013), Linville et al. (2012) recommend the development of a new brief screening tool as they suggest the SCOFF fails to capture all compensatory behaviours.

Studies show that physicians avoid screening due to a lack of referral options, fear of incompetence, or fear of offending their patient (Linville et al., 2010). In one study, Linville et al. (2011) identified that most practitioners will not diagnose eating disorders when a patient denies or becomes defensive upon questioning. They further found that 68% of participants do not screen for eating disorders when not a primary presenting problem. Citing previous literature, Banas et al. (2013) indicated that primary care physicians may avoid screening due in part to discomfort with knowing how to treat once diagnosed, thus concluding that better training will increase comfort with diagnosing and treating eating disorders.

Bannatyne and Stapleton (2015) examined the effect of educational interventions in reducing negative attitudes and stigma for eating disorders among fourth year medical students. Their study found that following educational workshops, participants exhibited reduced stigma, blame, and lowered negative perception of anorexia nervosa as a vain and selfish illness. The researchers point to education about anorexia nervosa as a promising approach to combatting stigma.

Psychology

Despite their integral role in eating disorder assessment, diagnosis, and treatment, researchers found no studies examining psychology practice in paediatric eating disorder care (Lafrance Robinson, Boachie and Lafrance, 2012). Existing studies have shown that psychologists more readily detect psychological over physical symptoms thus raising

concerns related to timely medical intervention (Lafrance Robinson et al., 2012). Despite wide acceptance of family intervention as best practice, research suggests that family members are not routinely included in intervention (Lafrance Robinson et al., 2012). Further, research suggests that stigmatizing attitudes continue to play into psychologists' perceptions of the nature and causes of eating disorders (McNicholas et al., 2016).

In a Canadian study, physicians' and psychologists' self-assessed competence, barriers, and needs were examined with respect to treatment of children and youth with eating disorders (Lafrance Robinson et al., 2013). Although the response rate was low (21.5%), findings showed that more than 90% had encountered patients for whom they were unable to treat due to a lack of skill, case complexity, and lack of resources. These findings raise alarm and highlight the need for better training in paediatric eating disorders. Findings suggest that practice barriers rather than logistical factors impede professionals' ability to intervene. Further, psychologists whose practice does not involve treatment for eating disorders reported low self-assessed competency related to diagnosis and treatment of eating disorders in children and youth (Lafrance Robinson et al., 2013). Those who showed high self-assessment (hypothesized to be related to specialized training) were most challenged by case complexity rather than lack of skill leading researchers to conclude that all clinicians at some point struggle with some cases (Lafrance Robinson et al., 2013).

Interdisciplinary Concerns

Caring for individuals affected by eating disorders requires an interdisciplinary approach to care. As research on the respective health disciplines show, each profession

has a unique role to play both within hospital and in community. Research related to doctors reveals the crucial role of this profession in screening and ongoing management of eating disorders. This can also be said of nurse practitioners who are assuming an increasing presence in primary health care. As the oral effects of eating disorders can be detected as early as six months, dentists are key to early identification and secondary prevention of disease. Nurses, both in hospital and at the community mental health level support individuals affected by eating disorders and are integral to education and treatment. In addition to playing a key role in obtaining the perspectives of families, social workers, guided by their code of ethics, assume an advocacy role both at the individual and systemic level. Registered dietitians have expert knowledge of the effects of nutrition on physiology and are essential component to eating disorder care. As experts in life roles, occupational therapists assist with concerns related to leisure, work, education, and social participation. Lastly, psychologists are trained in the assessment, diagnosis, and treatment of mental disorders including eating disorders. Psychologists provide essential counselling and psychotherapy to individuals and families.

Education and professional training related to eating disorders is a frequently cited gap for health practitioners (Banas et al., 2013; Hughes et al., 2014, McNicholas et al., 2016). Yet, how this knowledge gap influences attitudes and care for patients affected by eating disorders is not well understood (Currin et al., 2009). The importance of working as part of an interdisciplinary team is widely accepted (DeBate et al., 2006; Hart et al., 2011; Health et al., 2013; Linville et al., 2012; Pinzon, Anderson & Clarke, 2013; Shekter-Wolfson et al., 1997). Yet, collaboration is not without its challenges. As noted in research by Kendall and Hugman (2013), professional judgments made in the context

of interdisciplinary teams are influenced by the inherent and potentially competing values of the respective disciplines. Trust and cooperation between professionals is recognized as paramount to optimal care for persons affected by eating disorders (Kloczko & Ikiugu, 2006).

Early intervention is essential to preventing chronicity and treatment resistance and thus improves prognosis (Banas et al., 2013, LaFrance Robinson et al., 2013). Despite the critical role of families in intervention, researchers have discovered that family physicians do not regularly involve families in assessment and treatment for eating disorders (Girz et al., 2014). Prior research shows that parents are perceived as a challenge to treatment (Kloczko & Ikiugu, 2006) and a causal factor in the disorder (Weaver, 2012). While conversely, families are recognized as a positive resource for information as they know their child best (Bakker et al., 2011). Shekter-Wolfson et al., (1997) argue that flawed empirical research (e.g., over-reliance of patient self-reporting during the acute phase of illness, no evaluation of parental perception) has contributed to negative perceptions of the characteristics of families living with anorexia nervosa and bulimia nervosa. Parental involvement in intervention with paediatric patients is considered essential to successful outcomes (Weaver, 2012).

Developing therapeutic alliances with patients is considered vital to meeting the needs of individuals affected by eating disorders (George, 1997; Klockzo & Ikiugu, 2006; Trent et al., 2013). Understanding and validating patient perspectives is considered paramount in establishing and maintaining therapeutic alliances (Boughwood & Halse, 2010). However, interpretations based on generalized notions of the 'anorexic' with subsequent strong negative reactions persist due to a lack of education about these

complex disorders (Bannatyne & Stapleton, 2015; Boughtwood & Halse, 2010; George, 1997).

Patients do not typically present with a primary complaint of an eating disorder (Birmingham & Treasure, 2010). Further, as individuals affected by bulimia nervosa typically present with normal weight and without peripheral issues related to school or work (Birmingham & Treasure, 2010), professionals must avoid relying solely on physical presentation as a means of identifying disordered eating behaviors. Therefore, attention must be paid to signs suggestive of eating disorders, especially in young women (Birmingham & Treasure, 2010).

Persistent stigma, characteristic secrecy, and isolation make identification a challenge for professionals (Banas et al., 2013; Bannatyne & Stapleton, 2015; Trent et al., 2013). Specific challenges include high relapse, unrealistic view of body image, and patients' attempts at 'fooling the system' (Kloczko & Ikiugu, 2006). Screening for eating disorders is an important step in intervention (Linville et al. 2012). However, anticipating defensiveness from patients suspected of eating disorders is shown to stop health care professionals from screening (Linville et al., 2012). Training in eating disorders has a positive effect on primary health professionals' practice, which may in turn improve detection and intervention (Linville et al., 2012). However, time constraints can impede uptake of universal screening of eating disorders (Linville et al., 2012).

The importance of specialized care for eating disorders has been identified in research (Pinzon et al., 2013; Strober & Johnson, 2012; Treasure, Claudino, & Zucker, 2010). However, the perception that eating disorder intervention requires specialist skills is cited as barrier to professionals accepting to work with those affected (Weber & Davis,

2012). Feelings of isolation, lack of support, and the complexity of eating disorder presentations lead to a reluctance to accept referrals for eating disorder care (Weber & Davis, 2012).

Family based therapy (FBT), a clinical intervention aimed at helping parents to actively support weight gain and normalized eating (Hughes et al., 2014) is considered an intervention of choice for eating disorders for young families (Pinzon et al., 2013). Current research suggests that outpatient family based therapy is regarded as best practice for adolescents with eating disorders (Birmingham & Treasure, 2010; Dimitropoulos, Tran, Agarwal, Sheffield & Woodside, 2013; Hughes et al., 2014; Kloczko & Ikiugu, 2006; LaFrance Robinson et al., 2013). However, one research study suggests that implementing family based therapy is not without its challenges. Identified challenges include clinician doubt about its effectiveness, the requirement by pediatricians to adjust their otherwise prescriptive approach to care, and bias regarding the suitability of a specific family for FBT (Hughes et al., 2014).

Transitioning from paediatric to adult programs can be difficult for families who are accustomed to being involved in the circle of care (Dimitropoulos et al., 2013). Researchers therefore recommend that emphasis be on the developmental needs of the affected person and the readiness of the family to assume a less hands on, more supportive role. As general practitioners will eventually resume a primary role in eating disorder care, researchers stress the need for a shared care approach between paediatric specialists working with the young person and the general physician (Dimitropoulos et al., 2013).

Gaps in Research

Despite the significance of eating disorders among psychiatric conditions, there is limited literature related to practitioner knowledge, skills, and attitudes from an interdisciplinary perspective, and less so from a qualitative methodological approach. As such, conducting a literature search necessitated searching by individual profession rather than from the perspective of an interdisciplinary inquiry. Much of the literature refers to the need for integrated health care; yet, most research related to health professionals' experiences in treating eating disorders reflects the viewpoint of individual health disciplines. As we move to adopting more integrated health service delivery approaches to care, it is important to fill in the gaps in knowledge of eating disorders and the role that integrated care plays in optimizing treatment.

Chapter Summary

Eating disorders are highly complex psychiatric illnesses that require specialized care from trained health professionals. Despite our knowledge of the particularities of eating disorders, research suggests that eating disorders continue to be difficult to recognize and treat. Evidenced by current literature, interdisciplinary collaboration is key to optimizing care. Yet, challenges include competing professional values and fragmented care which can impede the formation of professional partnerships. We also know that families play a critical role in early intervention and treatment. However, research shows that families may remain outside the circle of care. Research shows that formal education and professional training needs are not being addressed and that current literature on the subject is more often from the view of a position paper or expert

knowledge rather than primary research. To better understand the shortcomings to care, researchers must focus attention to gaps in professional knowledge, and health practitioners must be empowered to participate in research.

Chapter 3. Methodology and Method

Introduction

Qualitative research is a methodological approach to scientific inquiry that “involves an interpretative, naturalistic approach to the world” (Denzin & Lincoln, 2005, p. 2). The aim of qualitative research is to bring attention to a social condition to better understand context and ramifications. Qualitative methodology is useful when a detailed understanding of an issue can only be established through direct observation or interviews with people, resulting in a more comprehensive, in depth knowledge of the issue under inquiry (Cresswell, 2013). Qualitative research helps to facilitate an exploration of issues through the subjective experiences of its participants. Qualitative approaches are appropriate when researchers seek to understand a social phenomenon for which little is known. Although potentially more time-consuming, knowledge derived from personal accounts of human experience can be very compelling and can advance the understanding of the social phenomenon under study.

Methodological congruence, a term coined by Morse and Richards (2002), is used to describe a qualitative design that is consistent in epistemology, methodology, and method (Cresswell, 2013). Epistemology, or the study of knowledge, denotes the “search for methods and foundations which enable us to be assured of the truth of our beliefs” (Polkinghorne, 1983, p. 10). Our knowledge, or understanding of reality, is distinct from beliefs and opinions and is developed within historical and cultural contexts (Polkinghorne, 1983). Epistemology refers to what counts as knowledge and of ways of

knowing (Cresswell, 2013), while methodology refers to the ways in which we seek knowledge (Denzin & Lincoln, 2005).

Methods are “the particular activities used to achieve research results” (Polkinghorne, 1983, p. 5) and include research design, sampling procedures, measuring instruments, and treatment of data (Polkinghorne, 1983). Choice in methodology, in turn, determines the method for gathering data. How data are then interpreted depends to a large degree on a researcher’s epistemic stance. Recognizing and respecting the interconnectedness of these concepts enhances all aspects of the research project from question formulation, interpretation of data, to completion of the written report. Ensuring the inter-connectedness between these three concepts is essential for assuring the credibility of qualitative research.

The intention of this research study was to employ a qualitative methodological approach to understand the experiences of health professionals who work with individuals affected by eating disorders in New Brunswick. To a certain extent, knowledge gathered from similar research contexts can be assumed to be reflective of NB health professionals’ experiences in providing eating disorder care. However, using local data helps to understand the magnitude of the care gap and to better understand regional barriers to knowledge (Graham et al., 2006). Understanding the experiences of New Brunswick health professionals in providing eating disorder care may help inform future regional service delivery and policy development. Through examination, we gain a better idea of the practice needs of health professionals caring for this population and the conditions that affect the care of individuals affected by eating disorders.

This research study employed a narrative, constructivist approach to research design and analysis. In this chapter, I examine the philosophical underpinnings and the appropriateness of narrative methodology for this inquiry. Within the methods section, I will provide a detailed description of the approach to data collection and analysis.

Narrative Methodology

Narrative inquiry is a study of the ways humans experience the world (Connelly & Clandinin, 1990). Narrative is both a methodology and a method. Narrative inquiry can be characterized as “an amalgam of interdisciplinary analytic lenses, diverse disciplinary approaches, and both traditional and innovative methods— all revolving around an interest in biographical particulars as narrated by the one who lives them” (Chase, 2005, p. 651). Narrative medicine, a leading development in medical humanities emphasizes attention to patient and physician stories as well as the co-construction of stories between the two (Solomon, 2015).

Narrative inquiry is based on the premise that humans lead storied lives. Central to narrative inquiry is the attention to stories that give meaning to persons lived experiences (Emden, 1998). As humans, we learn to understand and interpret our lived experiences through the stories we tell, re-tell, and re-live. The aim of narrative inquiry is to represent the stories of participants as they are lived and told (Duffy, 2012).

Clandinin and Huber (2010) posit that to think narratively requires consideration for three dimensions— temporality, sociality, and place. Temporality, a key feature of narrative (Elliot, 2005), refers to one’s relationship with time. Narrative is the meaning that is derived from the dimensions of time, including the past, present and future, for

both the participant and researcher (Clandinin & Huber, 2010). It is “punctuated not only according to one’s own life (e.g., one’s fiftieth birthday) but also according to one’s place within the long-time spans of history and social evolution (e.g., the 1980s)” (Polkinghorne, 1988, p. 126). Sociality refers to both the personal and social conditions of participants and the researcher. Sociality includes individual hopes, desires, and moral inclinations of both participant and researcher as well as the social and cultural contexts which exist relative in time to the unfolding events (Clandinin & Huber, 2010). Place refers to the physical locale where events transpire (Clandinin & Huber, 2010). For example, place may refer to a geographical boundary (e.g., New Brunswick or Atlantic Canada) or an institutional setting (e.g., a clinic or hospital). These three dimensions, or commonplaces, are important aspects of narrative inquiry. Attention to temporality, sociality, and place is required at all levels of the research process, from framing the research question, to entering the field, to composing field texts and research texts (Clandinin & Huber, 2010).

The role of a narrative researcher is to engage participants to tell their stories, and by so doing, the researcher becomes part of the process (Connelly & Clandinin, 1990). Although the story itself belongs to the participant, interpretation of the story lies with the researcher. Solidarity must be established between participant and researcher, along with the conditions that support an environment whereby both the interviewer and interviewee are engaged in understanding the important aspects of their lives (Polkinghorne, 1988). As Mishler posits “If we wish to hear respondents’ stories, then we must invite them into our work as collaborators, sharing control with them, so that together we try to understand what their stories are about” (as cited in Polkinghorne, 1988, p. 164).

However, data collection in narrative inquiry can pose challenges for narrative researchers. As identified by Chase (2005),

Narrative interviewing involves a paradox. On the one hand, a researcher needs to be well prepared to ask good questions that will invite the other's particular story; on the other hand, the very idea of a particular story is that it cannot be known, predicted, or prepared for in advance" (Chase, 2005, p.662).

Using empirical data elicited through observation, interviewing, and interpretation allows for a deeper, more holistic understanding of participants' storied lives, and the cultural and social contexts of their lived experiences. In narrative inquiries, data are the stories of participants. "The research does not construct a new narrative; it merely reports already existing ones" (Polkinghorne, 1988, p. 162). Core stories involve reducing full length stories into shorter texts to allow for thematic analysis (Emden, 1998). When possible, having participants review core stories can strengthen research results.

Appropriateness of Narrative for this Study

Narrative methodology is a helpful approach to eliciting the stories of social workers, dietitians, nurses, physicians, and other allied health professionals who have been entrusted to care for clients affected by eating disorders. Professionals can tell their stories knowing there are no "right" or "wrong" responses on their part. Empowering health professionals to share their stories allows for a better understanding of the context of eating disorder intervention and treatment in New Brunswick. Narrative inquiry was chosen as it allowed for a nonthreatening exploratory approach to the research question.

Constructivist paradigms assume that there are multiple realities. Constructivism “recognizes that all knowledge about ourselves and the social world is ‘constructed’” (Elliot, 2005, p.200). Embracing a constructivist paradigm allows researchers to be actively involved in the research process through questioning, clarifying, and inciting elaboration of discussion points, which facilitates the co-construction of knowledge. Everyone has a story to tell. Narrative methodology has proved useful for promoting a natural flow of dialogue, allowing participants’ stories to emerge unimpeded. Establishing an environment that allows for rapport-building and encourages open-ended questions and extended responses ensures that a participant is less likely to feel pressure to present him or herself through socially valued images (Polkinghorne, 1988, p. 164). In narrative inquiry, control remains with the storyteller, thereby empowering participants to share what they feel are the important aspects of their story.

By adopting a narrative approach to inquiry, participants were invited to tell their story in a way that allowed them to feel comfortable to respond to the research questions at the depth and breadth of participant choosing, without added tension. Inviting professional dialogue through narrative inquiry opened the door for an authentic account of participants’ descriptions of working with individuals living with eating disorders. These stories were analyzed to identify common threads and potential themes among NB health care providers. The findings provide insight into the needs of healthcare providers and have the potential to inform existing and evolving screening, treatment, and prevention initiatives.

By examining the distinctiveness in which New Brunswick health professionals live and work, we better understand their interactions, relationships, and responsiveness

to individuals affected by eating disorders. I was also able to observe and record the effects on the health professionals themselves, who had grappled with emotional and moral concerns, care gaps, and barriers to service delivery.

Methods

Choosing a methodology that would facilitate participants' untold stories to emerge can be a challenging aspect to qualitative inquiry design. I was aware of the vulnerability associated with asking participants to share their stories so that we may better understand what it is like to provide care to patients with eating disorders in New Brunswick. In health professions, as in research, professionals can feel disempowered and vulnerable when voicing individual experiences and perceptions of care, especially when those experiences differ from current dominant discourse on the subject. The challenge for researchers is to generate data without leaving health professionals as participants feeling de-valued by the process (Connelly & Clandinin, 1990). This point is particularly salient when the focus of the research is on professionals' knowledge and practice needs. As such, it was imperative that participants were not left feeling that their professional competencies were under scrutiny. Use of narrative inquiry provided an opportunity to elicit stories in a way that the professionals who participated in the study could maintain control of what information they shared and how it was co-constructed.

Research Design

A qualitative research design was used to elicit health professionals' experiences in providing intervention with individuals affected by eating disorders. For this study, the following questions represented the central areas of inquiry:

- 1) What are the stories of health professionals who provide services to persons affected by eating disorders?
- 2) How do health professionals conceptualize eating disorders, recovery, and provision of health services?
- 3) What are the knowledge and practice needs of health professionals regarding eating disorder intervention and recovery?

As a registered social worker, respecting participants' individual perspectives was core to individual exchanges with participants. A fundamental objective of this study was to establish with participants non-exploitative relationships that would lead to the development of a database containing the stories of health professionals who provide eating disorder care.

Sampling Strategy and Sample Size

A purposive, multi-site sample was recruited via on line classified advertisement sites, hand delivered posters, professional regulatory bodies and advertisements at health conferences, as well as by snowball technique, whereby participants assist in recruitment by identifying potential participants who may have knowledge of the subject matter under study (See Appendix A). The aim of the sampling strategy was to include all health professionals who would typically have worked with individuals affected by eating disorders and would be able to answer the research questions. This allows professionals to share their stories, conceptualizations about eating disorders and eating disorder recovery, experiences in health service delivery, and resulting knowledge and practice needs.

To be included as a study participant, health professionals must have met the following criteria: 1) English speaking, 2) professionally trained and registered with a New Brunswick governing body in at least one of the following health disciplines: medicine, nursing, occupational therapy, psychology, dentistry, social work, or dietetics, and 3) have professional experience in providing health care and services to individuals with an eating disorder. Prospective participants were provided a copy of the Qualitative Information Letter to help inform their decision to participate or not in the research (Appendix B).

Data Collection

Narrative inquiry involves eliciting stories of individual's lives resulting in a representation of personal experiences. In keeping with narrative inquiry, the primary approach to data collection was to engage participants in sharing their stories about their experiences as health professionals providing care to individuals with eating disorders in New Brunswick. My sample included multi-site, varied participants representing a range of health professionals involved in eating disorder care. Data were collected over a period of four months and I incorporated observations and reflections from preceding interviews as data collection progressed with new interviews.

Semi Structured Interviews

Prior to the commencement of each interview, participants were asked to read, ask questions, and sign the participant consent form, if in agreement (Appendix C). I completed the accompanying Researcher Statement at that time. Data were collected through in-depth, audio-recorded interviews using the open-ended interview questions as

a guide (Appendix D). Research interviews were semi-structured and lasted approximately 30-50 minutes in length. Except for one telephone interview, all research interviews were conducted face to face in the location of the participant's choice. Participants were advised of the focus of inquiry and approximate length of time in advance of the interview. Each interview began with the same question: Tell me about your experience as a health professional working with individuals affected by eating disorders. While each interview unfolded, attention was paid to ensuring that the three main areas of inquiry were covered: 1) participants' experiences, 2) participants' perceptions, and 3) knowledge and training related to eating disorders. Although a list of interview prompts was developed to generate discussion, the prompting questions were not required, and thus were not asked, except for asking at the end of every interview if the participant had anything more to add.

Data Analysis

In narrative inquiry, the aim of data analysis is to reveal common themes or plots in the data (Polkinghorne, 1988). Plots refer to themes contained within a story that, in turn, give significance to the story's events (Polkinghorne, 1988). During plotting, "temporal happenings are shaped into meaningful units" (Polkinghorne, 1988, p. 160). The plot is "a way of connecting event and story" (Polkinghorne, 1988, p. 131). To understand the ways in which health professionals in this study responded to health crises in their practice required careful examination of the individual-environment interaction in all its dimensions, giving attention to temporality, sociality, and place.

As individual stories have the potential to clash with the dominant social, cultural or institutional discourse, it was imperative to ensure that participants could not be identified thereby putting their professional reputation at risk. As the complex nature of individual lives become visible, I paid rigorous attention to ethical considerations as suggested by Clandinin and Huber (2010). This included paying strict attention to maintaining the anonymity and confidentiality of participants.

Procedures

This research reflects perspectives of eight health professionals from the aforementioned health disciplines. Research participants represented a wide range of practice settings, as well as a mix of experience in the treatment of both paediatric and adult populations. Although not expressly asked during interviews, most participants identified having practiced in their respective health disciplines for greater than ten years. However, their years of experience was not necessarily reflective of the years of experience working with the population under study. All but one participant was female.

Interview data were personally transcribed verbatim and anonymized to ensure confidentiality. Preliminary analysis involved listening and re-listening to tapes while being transcribed. This process was done close to the time of the interview to allow for deeper reflection of the data. Data were examined for themes in temporality and relationships. After a minimum of two transcript readings, the process of coding began. Code words were indicated in margins and later discussed with my supervisor, the principal investigator for the larger Atlantic study.

Analysis involved creating individual core stories unique to each participant's experience. A core story is a concentrated representation of a participant interview. Core stories were developed through a process of removing all repetition and extraneous content, including researcher questions, while retaining participant quotations. As stories typically do not unfold chronologically, the remaining field text was then re-ordered and refined, reflecting a beginning, middle, and end. The individual core stories in this research study are contained in Appendix E. From the individual core stories, I began the process of plotting both within and across the 8 core stories to determine the presence of commonalities within more than one story. A collective core story is a clear, credible account of how and why something has occurred (Polkinghorne, 1988). The collective core story, located in the findings chapter of this thesis, is an aggregate of the common themes and threads of individual core stories.

Thematic Analysis

Thematic analysis was completed using all participant interviews with an aim to identify and examine patterns within the data. This allowed me to accentuate threads common across all stories as well as those unique to individual stories. As Polkinghorne posits "the researcher's experience with many narratives allows him or her to produce a description that includes comparisons and contrasts within the story under consideration and between this and other stories" (Polkinghorne, 1988, p. 167). In this study, these unique and common threads were then integrated into a collective core story offering a detailed account of the participants' experiences.

Methodological Rigor

Research results need to be accurate, insightful, and ethical. Ensuring methodological rigor begins with the development of the research question. Rigor requires researchers to carefully examine their approach to data collection and analysis to make certain that emerging themes accurately reflect the data being collected and not the prior ideas, assumptions, and theories of the researcher. Assuring methodological rigor involves verifying participants' position and experience to make sure that participants are being understood.

Establishing Trustworthiness

Lincoln and Guba (1985) identify four criteria for ensuring trustworthiness for naturalistic inquiry: credibility, transferability, dependability, and confirmability. I used the following techniques to ensure trustworthiness and reliability of results. In addition, I used reflexivity and ethicality to enhance trustworthiness.

Credibility

Credibility, refers to the accuracy of research results (Lincoln & Guba, 1985) and was established through prolonged engagement, use of peer debriefing, and member checking. Prolonged engagement refers to "building trust with participants, learning the culture, and checking for misinformation (Cresswell, 2013, p. 250). Spending time with participants provided opportunity to build rapport and verify perceptions (Krefting, 1990). As a professional social worker with years of interviewing experience and an understanding of the context of health service delivery in New Brunswick, I entered the field as an accepted member of the group being studied that according to Lincoln and

Guba (1985) would enhance participant trust. Having honed my interviewing skills through years of direct social work practice, I was able to remain focused on participants' stories and to ask pointed questions that according to Chase (2005) would elicit clarification.

Peer debriefing, another useful technique for establishing credibility, focuses on probing biases, exploring meanings, clarifying interpretations, and testing hypotheses (Lincoln & Guba, 1985, p. 308). The 'debriefing' is typically someone knowledgeable in both the substantive area of inquiry and the methodology (Lincoln & Guba, 1985). Debriefing with my graduate supervisor, Dr. Kate Weaver, a well-published researcher in eating disorders and narrative methodology, was relied on as a further means to ensure credibility and dependability of research findings. All aspects of the study, from the research proposal and entering the field, to data collection and analysis were carefully supervised by Dr. Weaver, UNB Nursing Faculty.

Member checking refers to the formal and informal testing of interpretations and conclusions with members of the groups from whom the data were originally obtained (Lincoln & Guba, 1985). Informally, member checking was done during data collection by clarifying points made by participants during the research interview. Following analysis, individual core stories and a summary of the collective core story were returned to the participants who indicated a desire to see them and an offer was made to discuss the findings.

Transferability

Transferability refers to the extent to which findings can be transferred to other settings (Polit & Tatano Beck, 2008). Transferability is enhanced through gathering sufficient rich data so that researchers and others can see how the findings relate to them. Transferability is ensured when researchers provide sufficient context to meet the needs of other researchers or end users (Cresswell, 2013). Rich, thick descriptions allow readers to decide on the transferability of findings for their needs and purposes (Lincoln & Guba, 1985). The responsibility of the naturalist researcher is to provide a data base sufficient to make transferability of findings possible for other end users; however, judgement about its transferability lies with the end user (Lincoln & Guba, 1985).

The study's collective core story offers enough context to meet the needs of a research user and enough detailed description to allow end users to determine whether findings relate to them and their setting. Description was not limited to the thick rich data provided by participants but also included descriptions related to study sample and detailed descriptions of research methods, all adding to the transferability of research results. Having elicited stories from multiple angles at multi-sites and representing the seven health professions in the study design helped ensure that end users can assess transferability of results.

Dependability

Dependability refers to evidence that is consistent and stable (Polit & Beck, 2008). Prior to entering the field, I participated in a narrative methodology workshop designed for research students and research assistants. Following Lincoln and Guba's

(1985) description of dependability, I provided a detailed account of the steps taken and decisions made in this research process from entering the field to its conclusion. In this report, I describe in exact detail the methods of data collection, analysis, and interpretation of findings. Throughout the process, my methods for data collection and interpretation were monitored by my supervisor, Dr. Weaver to guarantee accountability to narrative methodology.

Confirmability

Confirmability speaks to the objectivity or neutrality of the data and interpretations (Polit & Beck, 2008). Confirmability refers to how well the results are supported by research participants and by the events that are independent of the researcher. Chapter six refers to the literature and findings by other authors that confirm the researcher's interpretations: this strengthens confirmability of the current study. Confirmability is realized with the data, and the interpretations made by the researcher are internally coherent and represent more than "figments of the researcher's imagination" (Guba & Lincoln, 1989, p. 243). Confirmability was further established through reflexive journaling.

Reflexivity

The concept of reflexivity relates to researchers' conscious knowledge of the biases, values, and experiences that are brought to the research study. Reflexivity is "the process of reflecting critically on the self as researcher, the 'human as instrument'" (Guba & Lincoln, 2005, p. 210). Reflexivity adds to research validity by explicitly juxtaposing researcher experience and interpretation with that of research participants. Referring to

maintaining an awareness of self within the research process, “reflexivity means the tendency to critically examine and to analytically reflect upon the nature of research and the role of researcher in carrying out and writing up empirical work (Elliot, 2005, p. 153). Using reflexivity throughout the research process to clarify if views reflect that of the researcher or participant is way to further safeguard methodological rigor.

As a profession, social work’s strength is in the ability to understand broad systems and to consider social contextual frameworks in analysis and interpretation of social phenomena. As a social worker trained in structural and feminist theory, my bias is to view complex social conditions as a bi-product of the inherent marginalization of certain societal groups in favor of the status quo. In addition to a write up of personal knowledge and perceptions of eating disorders prior to entering the field, I kept journal and field note entries as a way of reflecting on my observations and my role in the interview process, as well as a means of ensuring accountability and enhancing credibility of research results.

Ethicality

Ethicality in research refers to the ways in which research procedures adhere to the professional, legal, and social obligations to study participants (Polit and Beck, 2008). In this study, ethicality was achieved in the following ways: protecting participants from harm, ensuring the research had a clear purpose, managing risk, protecting confidentiality, and ensuring informed consent.

This research study was reviewed by the Research Ethics Board of the University of New Brunswick. The rights of all participants were cared for in accordance with the

ethical guidelines outlined in the Tri-Council Policy Statement (TCPS2) on Ethical Conduct for Research Involving Humans (2014) and the University of New Brunswick Research Ethics Board (REB). As part of the graduate school requirements in the Master of Applied Health Services Research program, I completed the Ethical Foundations of Applied Health Research course. In preparation for entering the field, I completed the TCPS2 certification course on research ethics (Appendix F). As a registered social worker with the New Brunswick Association of Social Workers, I adhered to the principles and values of the Canadian Social Work Code of Ethics (2005) which guides professional conduct by promoting honesty, reliability, and impartiality, and respecting trust and confidence. Further, I strictly followed the principles outlined in the Code of Ethics related to social workers who engage in research, including minimizing participant risk, ensuring informed consent, maintaining confidentiality, and accurately reporting research results (Canadian Association of Social Workers, 2005).

In accordance with Section 2A of the TCPS2, the following formed part of the data collection procedure: 1) informed consent by means of a comprehensive qualitative information letter, 2) the option for participants to discuss the study with the Principal Investigator and Supervisor at their request, 3) minimal risk due to the nature of the interview discussion, and 4) the option not to participate or to withdraw from the study at any time without negative consequences. The decision to participate in the study rested with the participant and was free from coercion.

To ensure confidentiality of participants, all research data, including audiotapes, research notes, and signed Informed Consent forms were kept in a secure, locked cabinet in my office during the study. Interview transcripts were stored separately from consent

forms to ensure anonymity. After the study, data were transferred to a secure, locked cabinet in the office of Dr. Kate Weaver, research supervisor and Associate Professor, University of New Brunswick, Faculty of Nursing. The research information will be retained for a period of seven years following completion of the study.

Chapter Summary

Narrative inquiry was shown to be a helpful approach to better understand the context and setting of eating disorder care in New Brunswick. Narrative inquiry proved useful as a way of empowering health professionals from the seven regulated health disciplines to tell their stories of providing care for someone who is affected by an eating disorder. Through semi-structured interviews and the development of a collective core story, participants and researcher succeeded in creating a co-constructed account of the lived experiences of health professionals providing eating disorder care in New Brunswick.

Chapter 4. Working the Method

As a qualitative researcher and allied health professional, I am aware of and interested in the multiple perspectives of health professionals' experiences in service provision. Having worked in health and social services in a largely remote and rural province, I have tacit knowledge of the interconnectedness of health and social service professionals at different levels of service delivery. I am also keenly aware of and interested in the interplay between care providers and care recipients.

Participant recruitment for the study of health professionals' perceptions of working with individuals with eating disorders has proved difficult. As researchers, we are often observers of social interaction; largely from the perspective of an outsider. This can prove challenging in a province, like New Brunswick, that is largely insular in character. To seek personal accounts of professional experiences in a culture that is largely uncomfortable with disturbing the status quo can be a challenge. As a result, eliciting perspectives of service providers can be risky for health professionals and very challenging for researchers. We live and work in an environment that is opposed to opposition. As such, some demographic groups are woefully under represented. Individuals with eating disorders and their families are one such group. Amassing rich qualitative data is integral to understanding the complexity of care for this largely underserved population.

Recruiting professionals to share their experiences for research purposes, so that we may better understand the social, cultural, and political contexts was difficult for other research assistants working on this project. Yet, as a new researcher, I could recruit eight research participants, representing each of the identified health professions, in a span of 4

months. Moreover, the data obtained was of such rich quality that it will positively contribute to a better understanding of the enigmatic nature of care for individuals with eating disorders in the province.

I attribute my ability to incite such a favorable response, in part to the fact that while I may be an outsider as a researcher, I have been part of the inner circle of care in this province for more than 20 years. My familiarity with the culture and the various 'systems' helped to quickly establish trust and rapport with participants. I am also keenly aware of the sense of vulnerability that comes with attempting to change public discourse on what is and what should be, especially in relation to marginalized groups. This familiarity enabled me to identify the subtleties of participant responses and to adjust my questions accordingly, without having to rely on scripted prompts.

Clinically, my interview style has always been to go where people lead. My approach is to seek to understand diverse individual experiences or understanding of social situations. It is only from opening our minds and our ears to the stories of others, even when they differ from our perspectives, that we can gain appreciation of the particularities of individual lives. Interestingly, until I entered the field, I was unaware of how important this approach is to research interviewing as well. In fact, I left the first interview feeling dismayed by the process and outcome. The interview dialogue felt tangential and off topic and left me feeling like I did not garner much insight into that professional's experience on the subject. However, reflecting on my first interview, I came to appreciate that the peripheral information, seemingly unrelated, was core to understanding that health professional's experiences and approaches as a practitioner who has cared for individuals with eating disorders. In hindsight and upon analysis of this

professional's story, I have come to realize the importance of listening and allowing for a natural flow rather than controlling the dialogue.

As researchers, we must be able to depart from the scripted prompts if we want to learn about people's stories. We cannot predict in advance what will be shared. It is only through active listening and asking thought provoking questions based on what we are hearing that we will come to learn and appreciate the subtle nuances of individuals storied lives. Only then can we understand that this information, which may seem tangential or off topic, is integral to the narrative.

My approach to data collection was largely through snowball technique. Initially, I reached out to former colleagues in the various health disciplines to share my involvement in the research study. Because of these informal discussions, potential research participants were identified. Some potential participants were approached by their disciplinary colleagues while others were identified by the participants themselves. Through the process of interviewing participants, I would become aware of others working in this area and would then reach out via email to share information about the study.

Although, I cannot say with certainty, I believe my relationship building skills and my reputation as a collaborator helped to facilitate connections to potential participants. I did not have expertise as a researcher, nor as a clinical expert in the subject. Therefore, having shared my own limitations of knowledge on the subject and assuring potential participants that I was looking to understand their professional knowledge and experience on the subject may have lessened the intimidation factor and helped with recruitment. During the recruitment phase, I made it clear that my aim was not to judge competence

and that although one of the criteria was to have experience working with this population, I was not necessarily looking for someone with expertise in eating disorder care. Of note, most potential research participants were identified because of their experience, passion, and knowledge of eating disorders or because they had a particularly salient story related to their experience in caring for individuals with eating disorders. As a result, I could gather very detailed accounts of professionals' experiences, perceptions, and training related to eating disorders.

Interviews were conducted in the participants' naturalistic environments which likely contributed to the ease of dialogue. Only one interview was conducted by phone, at the request of the participant. All others were held in participants' work locations in community, hospital, and clinic settings. As I have worked in both the community and institutional level, I was not daunted by conducting interviews in the work environments of participants. Interestingly, as I waited in the common waiting area for one participant, a rather agitated patient was swearing, banging and kicking doors and walls. Although, a bit unnerving as I was alone, it was not enough to affect the ensuing interview. This may have had a different effect on researchers accustomed to more controlled, quiet environments.

Having experience as part of multidisciplinary healthcare, I am familiar with the roles of various health disciplines in the circle of care and so could ask more specific questions pertaining to each discipline. As a new researcher, observing the passion and energy from participants was powerful— especially from those who could identify the injustice of care provision for this group or for the lack of support for themselves or their colleagues. I think my interview skills as a social worker, helped to facilitate these

authentic accounts of their personal experience. As a seasoned health professional, participants' energy was not off-putting nor were their stories particularly shocking. In fact, at times, their experiences and frustrations mirrored my own.

Interviews progressed (often quickly) from more benign accounts of training and formal education to detailed, passionate dialogue about the fragmentation of care and gaps in service delivery. Being accustomed to people's energies helped me to remain centered and focused on what was meaningful to participants, in a way that was gentle and respectful. In research settings, respect involves "caring for others, honoring them, and treating them with dignity" (Denzin & Lincoln, 2005, p. 37) Now, as the steward of their stories, I feel compelled to carefully share their stories and to protect the professional integrity and identity of participants who entrusted me with their experiences and stories. These are powerful confessions, to a fellow colleague, in a province so small. I am humbled by the level of confidence that they entrusted in me by exposing their vulnerability through disclosing that they did not have all the answers or maybe missed signs or made some mistakes in order that others may learn. I now feel a responsibility to gently care for their stories in the same spirit that I entered the field, free of judgement, so that we may all learn, and so other professionals may feel less isolated and individuals may receive better care.

Chapter 5. Research Findings

The following is a collective representation of eight New Brunswick licensed health professionals' experiences in providing care and support to individuals affected by eating disorders. Participants represented the fields of dentistry, medicine, nursing, dietetics, social work, psychology, and occupational therapy. Reflecting the original scope of the project, findings were aggregated to protect patient identities and shield respective health disciplines.

The central finding of the study of health professionals' experience concerning eating disorder care in New Brunswick portrays a maze of care, complicated by the many faces of eating disorders and the patchwork of services offered within the health system. From the data, two distinct themes have emerged: 1) **the nature of eating disorders** and 2) **the valuing of health care priorities**. It is through these two themes that the collective core story, seeing beyond the eating disorder emerges for professionals (Figure 1). This process is rooted in the social and cultural environment that influences understanding of eating disorders and response to care. The model is a graphic representation summarizing the major findings. It shows the relationship between the two themes, the *nature of eating disorders* and the *valuing of health priorities*, and the subsequent process that health professionals go through when providing eating disorder care. Although arranged in a linear fashion, the two themes, the nature of eating disorders and the valuing of health priorities are not a linear process. As the model shows, seeing beyond the eating disorder is a graduated process that begins with tension and culminates in overcoming obstacles to care (See Figure 1).

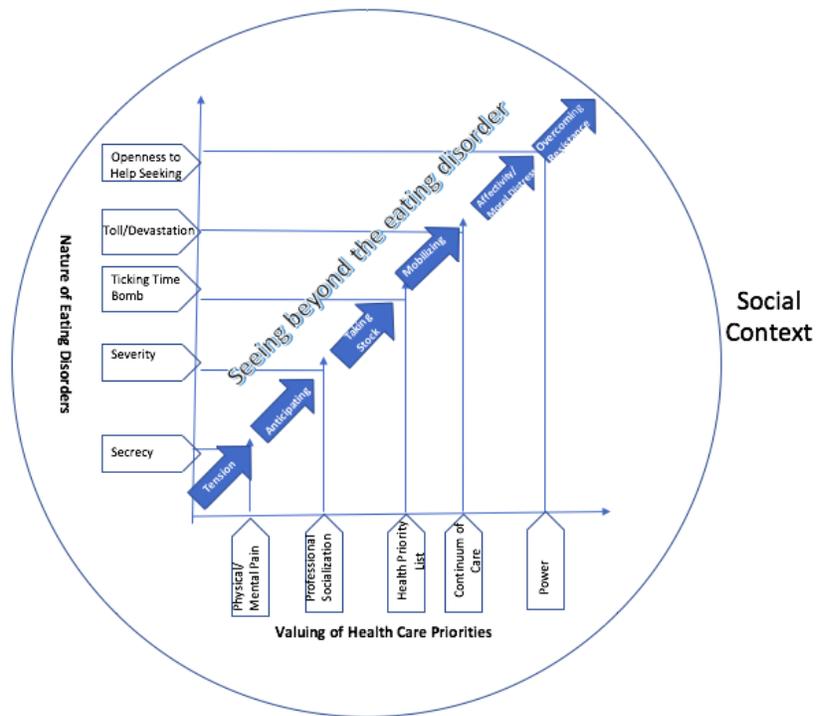


Figure 1. Understanding the Social Context of Eating Disorders

Encompassing the two central themes, the nature of eating disorders and the valuing of health priorities is the social and cultural environment in which eating disorders develop and within which eating disorder care is provided. Although there is no one single cause of eating disorders, it is widely accepted that the social and cultural environment plays a role in fuelling eating disorders for those who are susceptible. According to one participant, “A big problem for the younger kids lies in media messages and wanting to emulate stars and models that are stick thin. Standards that most people can’t attain.”

Every day, such persons are flooded with messages about how to look and what to eat. To illustrate how challenging it can be to sift through all the nutritional information available, one participant had this to say, “There is a lot of news around gluten, starch,

and portions. People think this information is truth. Even I question myself and I know better. How much more is it going to affect someone who doesn't know?"

Social media messages abound and play into ideas of what it means to be successful, in control, and popular. Images depicting body ideals are everywhere, contributing to body image dissatisfaction. Desire for thinness by girls and women and conversely, desire to be buff and lean by boys and men, leave some susceptible to engaging in risky health behaviors as an attempt to attain the body ideal.

There was a medical resident at my gym and she would be sweating it up on the stair climber. I could see all the bones down her back and her shoulder blades. She had a really drawn-in look and I just knew she had an eating disorder.

Working in this social context that values thinness, health professionals cannot escape the predominant social and cultural influences and their effect on opinions, beliefs, and ultimately, professional practice. As a result, these influences can play into the identification and treatment of eating disorders.

In terms of understanding, initially I would fall into the same category as most of the public, thinking that eating disorders were simply a cry for attention and really minimizing the impact it has on families. Learning about the condition has really changed my perception, including society's role in creating this ideal body image that people strive for, and looking differently at the multi-million-dollar diet industry.

Nature of Eating Disorders

By their very nature, the diverse manifestations of an eating disorder can challenge professionals' ability to recognize and respond. For participants in this study, eating disorders have presented as "poor eating," "too much eating," or "not eating." They have also appeared as a preoccupation with a particular weight or dress size. As one participant said, "I have clients who want to get to a size 2. Or one lady that wanted to be 100 lbs because it's a nice round number."

Sometimes eating disorders have presented as strange food habits or food restrictions, like one participant's patient who "would not touch anything on her tray and would only eat pretzels brought in by her mother." Another participant indicated that "not wanting to take a medication because she [the patient] has to take it with food was a screaming red flag."

Those affected may be emaciated or malnourished but obese. As stated by a participant, "I've had some morbidly obese clients and their idea about losing weight is not eating or eating one meal a day. They will never get to the point where they would be emaciated but it can still affect their health." While for others, individuals who present as "very, very, very tiny" but "proportional" and "well put together" makes identification and treatment a challenge, especially when they deny a concern.

Professionals are puzzled by the enigmatic nature of eating disorders which challenges their ability to accurately identify an emerging illness. Although study participants indicated that most of their patients with eating disorders are teenagers and young adults, eating disorders can present at any age as this participant quote illustrates, "I've seen people from the age of eight, all the way up to the age of fifty-three."

Participants were quick to point out that there are many faces of eating disorders and this complicates identification, early intervention and treatment. As one participant observed,

Athletes are a whole other kettle of fish. I see girls and guys who come in talking about their training and diet and who want to see a dietitian because they need certain calories and a certain protein to build muscle and make themselves very lean. They are working out a lot. We don't tend to think of it or label it as an eating disorder but if you get down to the nuts and bolts of it, it's very restrictive.

As eating disorders can appear with different faces, professionals must be in tune to what is being said and what is not readily disclosed. Through analysis of the first theme, the nature of eating disorders, the following narrative threads were contained: *secrecy, severity, ticking time bomb, toll and devastation* and *openness to help seeking*.

Secrecy

For health professionals in this study, one of the biggest challenges to care is that the disorder is often veiled. Secrecy obscures professionals' ability to identify the illness. Signs are often hidden from view and not readily discussed. As participants emphasize, "It's really hard for them to disclose." Seeking treatment can be difficult as "they have a hard time naming it." Further, "there is a lot of stigma attached to eating disorders" which can also impede help seeking.

Initially, symptoms may be present but get missed, either by family or health professionals, or both. Sometimes the focus is on co-morbid conditions, like "gastric reflux," "epigastric pain," "anxiety," or "depression" and the eating disorder is not recognized. The eating disorder "is not always something that the patient wants to talk

about” but comes out in conversation while receiving treatment for another mental or physical health issue. For one participant, it took time to build rapport before the patient disclosed her concern, “I had been seeing her for a number of months for depression, anxiety and physical issues. Finally, one day, after 45 minutes, she blurted out that she thought she had an eating disorder.”

According to participants, “denial is a primary response” from patients. As one participant stated, “When I notice red flags, I try to bring it up but they deny or do not want to talk about it.” Denial can complicate intervention, especially if the person is being treated for a different ailment. Consequently, health professionals find themselves at a loss about how to proceed. “That’s the challenge. I am kind of caught. I don’t want to push in a different direction if my patient is already being treated for something else.” Thus, the secretive nature of eating disorders complicates taking early action.

Professionals rely on active listening, problem solving and open communication to facilitate discussion. Sometimes health professionals may recognize a discrepancy between physical and mental cues and what is being said. “Things don’t make sense or tie together. It’s the incongruence. There are certain things the body does that sort of jump out as being off.”

Patients who are open to talking about their concerns are easier for professionals to engage in treatment and may, in the view of one participant, be functioning better as patients who do not disclose pose a bigger risk, “The sicker patients are the ones that are better at keeping it under wraps.”

Recognizing warning signs and knowing “the best approach to take and the best things to say” are important for professionals. Some have learned to approach situations

cautiously, otherwise “everybody panics” and the suggestion of an eating disorder is “automatically shut down.” As one participant said,

I have to watch my approach. I usually sort of quiz a little bit to see what I can find without actually talking about it. I have learned to watch the body language and facial expressions and have tried to make it a ‘non-approach’ in order to find out more information and to open the door.

Severity

As the illness advances, eating disorder symptoms become more visible and harder to ignore. Those affected can become socially withdrawn and struggle to remain active in school, work and leisure activities as was the situation for this participant’s patient, a young woman who “very quickly got very sick and had to stop every activity. She was not socializing or going anywhere, couldn’t work and had to leave university.”

Professionals describe the progression of the disorder as “debilitating” as patients are sometimes “starved to the point of experiencing scary symptoms.” One participant pointed out “the [patient’s] system is so used to being sick all the time,” while another explained, “Sometimes they couldn’t even walk to the bathroom. They needed a wheelchair.”

Reflecting on one particularly challenging and frightening referral, a participant indicated that her patient became “really, really sick” and “in fact, she almost died twice while under my care.” Because of its lethality, anorexia nervosa can be particularly difficult for professionals requiring a heightened level of response from the care team.

The files that stand out as extremely challenging are those patients diagnosed with anorexia nervosa. Their mortality rate is the highest. Their risk of dying is more than our other clients. I have even had doctors admit that a patient is pretty thin but it's just dismissed. And I think, 'wow' we need to address this now. It's kind of the elephant in the room.

Ticking Time Bomb

Participants stressed the time sensitive nature of recognizing and treating eating disorders. Quick and intense treatment is required.

I once told a referring psychiatrist that the youth needed a paediatrician and a dietitian before I would even start therapy. This psychiatrist did not have admitting privileges and the youth didn't have a paediatrician or even a family doctor. I thought to myself, how are you going to get this youth on paed [paediatric unit], if God forbid, something happens to her medically? This is a ticking time bomb.

Early detection can allow for a more "preventative" role focussing on "educating patients." As one participant said, "If pediatricians or family doctors can make a referral as soon as there are warning signs, I find that works better." Further, "catching them early" may avoid the need for hospitalization or additional complications.

You want to get a hold of this in the first two years. I have worked with some youth who are three plus years in their disordered eating patterns. At that point, behaviors are so entrenched and families so depleted that it makes it difficult to do out-patient therapy.

As the disorder progresses, it begins to affect individuals socially, emotionally and physically. When they are sick “their brains aren’t functioning” and their “heart may give out” making therapy a challenge. Once the disorder takes hold “Patients are under the control of the illness and are not able to think straight or make decisions that are in their best interests.” The situation becomes “high risk” and “complex.” As one therapist identified, “There are a lot of issues that need medical follow up and intensive resources.” More immediate, and sometimes more intrusive action needs to be taken. The illness also begins to affect family functioning. One participant highlighted an extreme situation that necessitated a referral to child protection “because [the child’s] behaviors were so challenging and the parents were unable to do it [the care].”

Participants highlight the need to respond early to avoid having the illness become entrenched or life-threatening because once that happens “we are in big trouble.” As the affected person becomes more acutely ill, professionals and families begin to recognize that death is a real possibility. It is at this point that professionals sense that “their [patients’] lives are in your hands.” As one participant put it, “It’s a serious, pervasive condition. If left untreated, they can die or continue to have issues into adulthood.”

Toll and Devastation

As the disorder progresses, the toll and devastation on patients and families becomes more pronounced. Lives are in upheaval. Professionals point out that pain and suffering are not limited to the affected person but extend to the entire family unit, permeating all aspects of their lives. Parents, whose lives are in turmoil, need their own

support, “A lot of our parents are so depleted that they are seeking services for themselves, marriages are breaking down and siblings are being neglected.” Participants observed that parents are “so burnt out” and “so tired” that by the time the child is admitted to hospital, parents are “a mess.” The toll takes many forms as this quote illustrates,

The struggles that families face when trying to help their children are not just emotional stress but a financial burden as well. There is a financial cost to leave work, put gas in the vehicle and drive to the hospital two hours away, and to leave other children at home and make arrangements for their care.

Whether in community or in hospital, parents are expected to take an active role in treatment. This is challenging for parents who already feel overwhelmed and culpable. One participant summarized the intensity of parental self-blame and exasperation in the following quote,

Parents’ level of exhaustion was obvious. As parents, your instinct is to feed your child, to take care of and nurture your child. And when parents can’t do that, it’s actual torture and suffering on the parent. I don’t think there was one parent that didn’t say ‘why didn’t I notice or do something sooner?’ Or ‘clue in?’ There wasn’t a single parent that didn’t blame himself or herself and ask why they were not able to feed their child. There is something about not being able to feed your child that does something to parents.

Openness to help seeking

Individuals beginning the process of recovery are vulnerable. Participants identified that sometimes, but not always, the eating disorder “results from a trauma.” Although eating disorders are not about food, food becomes “that piece that they can control.”

Treating an eating disorder means changing one’s environment. Individuals and families require a lot of support as the situation “can get volatile.” The affected person can become “resistant,” “oppositional,” and “angry” in response to imposed measures. “As soon as you start the process [of change] everything comes out and the whole system is shaken up and under tremendous stress.”

The therapeutic process can be difficult given that food is life sustaining and thus cannot be avoided, “Calories tend to be what people are most afraid of as they think they are either going to exercise or body fat” when in fact, calories are necessary “to keep our heart pumping and kidney filtering.” As one participant stated,

I tell them it sucks that this is your addiction because you have to learn to manage it. Whereas we would never tell an alcoholic ‘well yeah, keep the bar stocked at home but just don’t have any’ or learn to manage it in moderation.

Understanding “energy input and output” and “healthy nutrition” are important aspects of recovery. “Body image,” “self-esteem,” and “communication” are also necessary components of therapy. Participants advise that individuals and families need education about the effects of the disorder on their oral health, physical health, mental health, and social wellbeing. Even with treatment, individuals, families and professionals need to remain vigilant as recovery can be a long road.

One client came back from an eating disorder clinic so she had lots of counselling. I remember that she was still measuring everything to make sure she was getting the amounts that she was supposed to be eating. After a month or so, she said that she is not really measuring right to the top. She still had those habits of needing to reduce intake. It was still engrained in her mind that she had to lose weight somehow. She would tell me about how she hated looking at herself in the mirror. Even though she had gone to counselling, she still had poor body image.

Family involvement is needed to improve outcomes and promote “patient buy-in.” Some parents are “over-protective” while others “tend to minimize.” Although essential, involving families in the care is “taxing” on already “depleted” parents. As one participant remarked, “The Maudsley approach is beautiful in theory. But my heavens, these families need to be ready and able to do the work.”

Families need education about what to expect and guidance on how to cope with the challenges that arise through treatment. “Every family’s worst fear is the most severe outcome, which is death.” Knowledge of eating disorders can help families with recovery. “Often families will think, well just start eating or stop purging.” Parents often experience push back from the affected person. Often “people pleasers” or “the protector of the family,” this is typically “the child that parents did not have to worry about.” Families must learn to separate the eating disorder behavior from the person and learn to set healthy boundaries.

One mother was amazing! From the beginning, she was the one who noticed her daughter’s changes and went to the doctor to advocate for her. There was just no

messing with this eating disorder. This mom had such a fierce approach to the eating disorder. She was able to separate her daughter from the disorder but had very clear boundaries. She knew the signs. Having that education seemed to provide that extra advantage.

The theme, the nature of eating disorders, conveys the notion that these puzzling, secretive, potentially rapidly progressing, and lethal disorders can pose significant challenges for health professionals. Professional involvement at the onset of illness may help to minimize complications, treatment resistance, and illness toll on individuals and families. These findings call attention to the need for health professionals to better understand the characteristics of eating disorders, with emphasis on early identification and appropriate, timely intervention to improve health outcomes.

Valuing of priorities in the health care setting

As eating disorder symptoms become more visible and illness toll becomes more pronounced, professionals begin to plan how and when to access services. Yet as this study shows, linking those who need it to eating disorder care is a challenge. The second overarching theme relates to the valuing of priorities within the health care setting. Through analysis of the second theme, the following threads emerged: *addressing physical and mental pain, limitations in professional socialization, confronting the health priority list, managing the continuum of care, and power ramifications.*

Physical and mental pain

Conventionally, the health system response is built outwards from physical pain. As a result, the quality of mental health care has historically lagged that of physical care. Consequently, physical complications of illness, for example epigastric pain and cardiac issues, are more readily recognized and responded to, over less overt mental health symptoms, like emotional distress and self-harm. As one participant observed, “She is being treated for gastric reflux but it is obviously not just gastric reflux. She is malnourished and underweight. It’s anorexia.” Another participant provided the following example, “For her, she started vomiting after eating because it would relieve her epigastric pain. She also has a history of self-harm. I think that the vomiting became another way to relieve her physical and mental pain.”

Professionals attempting to facilitate access to eating disorder care struggle to find resources until it reaches an alarming level, leaving both professionals and those in their care vulnerable. “There are no resources. I’ve sent people to the hospital in the past and it doesn’t work. Unless they are medically unstable, they are not going to get a bed.”

Professional socialization

Professional socialization refers to attitudes, skills, knowledge, and beliefs acquired through training, experience, and professional exposure. Professional socialization has a profound effect on patient care. As one participant highlighted, “even one small, misinformed comment can cause harm.” Professionals’ ability to recognize and their readiness to respond is directly attributable to their understanding of eating disorders, as the following quote illustrates:

Some paediatricians are awesome and totally get it, while other GP's [general practitioners] and paediatricians will shy away. Some family practitioners don't see it as concerning as we do. And, some paediatricians openly state that it is more of a mental health issue and it is not something they feel specialized in.

All participants in this study identified inadequate formal training and ongoing professional development. Participants indicated that they had little or no specific formal training on eating disorders. During their formal training, participants indicated that eating disorder learning consisted of a "quick run through" but one participant stated, it was "nothing I could tap into from memory." Participants have discovered a general dearth of knowledge and professional resources. For example, "When I asked a colleague in another region for resources, the emailed reply was a link to two websites. That gave me a flavor that everybody else must be struggling with their knowledge, too."

Participants identified several ways that they addressed gaps in learning. Although not ideal, participants indicated having to "learn by myself along the way" or to "self-teach." Others addressed the gap in knowledge by "doing my own research," "consulting colleagues," or having "peer supervision" with someone more skilled, sometimes in response to a challenging scenario. One learned through "co-therapy" while another learned through observation while working with a dietitian with experience and training in eating disorders. For this professional, she "would read her [colleague's] assessments and would start to say, 'okay now here are the questions that she is asking that is bringing that out more.'" More than one participant indicated that they had consulted specialists out of province, "I did a lot of consulting with an out of province

eating disorder team. One case was so scary that I would consult because there was no one here.” As one participant stressed, even with experience in eating disorder care, professionals can feel like they are “treading water.”

Several participants indicated a lack of availability of “good” workshops that focus on eating disorders in general, and their area of practice specifically. The issue of lack of training dollars was also identified. Limited professional development funding restricts how far professionals can travel and who can attend, leaving professionals, as one participant said, tongue-in-cheek, “to draw straws to see who gets to go.” Professionals articulated trying to do the best they could with the training and skills that they had, relying on scarce resources to guide and support them in their effort. As an offshoot, participants sheepishly admitted to having maybe missed a diagnosis or having contributed to sub-optimal care at some point because of lack of training and knowledge of eating disorders.

It would be easy for the dietitian to say ‘no, this is what you are eating’ and I would be trying to ‘advocate’ for the patient to make more of her own choices. But that would not have been the right thing to do and would have caused more trouble. At first, I probably did some of that, until I realized, wait a minute, I don’t really know what I am doing. I’ve heard some health professionals even say things like, ‘you just need to eat right’, or ‘you need to just eat like a normal person.’ It’s not that they are ill-intentioned. It’s just that you need to have education about what actually an eating disorder is. Without that, you’re walking in the dark.

Health Priority List

Frequently characterized by programs that are underserved and underfunded, mental health has been the orphaned system within healthcare. Mental health care in general, and eating disorders specifically, have not been prioritized under current health services. In the words of one participant, “The medical community does not seem to be able to come together and advocate for patients. You are either insulting a colleague or questioning the politics of it all.” Only when pushed, does the system seem to respond and only for the time it takes to stabilize a person, and then return them to the community to manage on their own. Consequently, New Brunswick health professionals are left to diplomatically create and implement a plan of care from the patchwork of services that exist.

I was probably at that home twice a day for the first two weeks, training agency workers and showing them what to do. That’s way out of scope of what I am supposed to be doing and it isn’t ideal. The patient should have been staying in hospital. We were just doing the best that we could.

Rather than mobilize resources to research and implement effective interdisciplinary treatment programs, these findings suggest that eating disorder care is for the most part just avoided all-together.

I was mad about it at the time. I can’t think of another diagnosis where I don’t have someone to call. If I have something surgical, I have a surgeon. If I have a lung problem, I’ve got—. In this situation, this was a psychiatric diagnosis that psychiatrists don’t see. This is what is different from other disorders.

Continuum of Care

Closely following health priority lists, are issues related to the health system's continuum of care. "There is no coordinated approach to care" leaving professionals to cobble together supports on their own. As one participant said, "These are huge files. We can't be working in separate silos. We all need to be working together."

The responsivity of the health system is guided by symptoms, both as an in-patient and out-patient. Sometimes patients are discharged too soon. As one participant put it, "We know what the health system is like. Once someone is medically stable, they are going to go home but are still very ill." This participant pointed out that a consequence of early discharge is that "basically, parents end up providing hospital care at home." Another participant echoed concerns related to premature discharge, "We've come across instances where patients were discharged when they shouldn't have been as there continued to be issues playing into the eating disorder behaviors."

A lack of consistency and fractures within care teams can add to the "frustration" for both professionals and families. Finding "consistency among team members can be challenging" leading to "professionals disagreeing." This results in "mixed messages" for patients and families which creates further angst. Discharge from hospital can also be a pressure point. "In hospital, patients have a team." However, "coming up with a comprehensive plan" at discharge can be difficult because "it is hard to find good resources." Fragmented services further disrupt continuity of care. "The fragmentation of care makes things difficult. Continuity is huge when you are working with someone with a condition as complex as an eating disorder." While another stated, "When we went

looking for resources, we found little pockets of individuals who treat eating disorders but there is no coordinated clinic or program. And that is what is required.”

Lack of private medical coverage also affects the continuum of care. “In hospital, we try to find out where best to send people in the community. If patients don’t have private coverage, they have to pay out of pocket.” As one participant noted, a lack of options adversely affects outcomes for individuals who cannot afford to pay for private therapists, “The ones that can afford to see me weekly, progress more and have a better chance of getting better.”

For those who require it, out of province travel is the only option for specialized in-patient eating disorder programs yet in the words of one participant, “I know colleagues who have referred out of province for eating disorder treatment and out of province billing is another issue.”

In rural communities, availability and proximity to services add to issues of access. The many challenges to care in rural communities is summarized in the following quote:

In rural settings, it is extremely difficult pulling resources together. I don’t just work with people with eating disorders. I cover both out-patients and in-patients and work in three different facilities. We have tried accessing the social worker at our local facility but that didn’t really pan out. There are private psychologists but you’ve got to have private insurance coverage.

Power

Underlying all threads in the theme valuing of priorities in health care settings is the issue of power. From the stories of participants, it is evident that power dynamics play out at every level— from what gets funded and why, to valuing physical symptoms over ones perceived as self-harm, to opportunities for professional development and training, and lastly, to the lack of dedicated in-patient and community resources for eating disorder care. “What definitely stands out is this pointing match of who is supposed to be working on this file. There ends up being this divide with medical practitioners and hospital and community mental health.” Professionally, who gets recognized; who gets intimidated, silenced or ignored; who is granted admitting privileges; who gets invited into the circle of care and under what circumstances; and which disciplines get called to the decision-making table are all examples of power dynamics at play in health care. And at the heart of it all, is the individual and family whose lives depend on that care.

One young girl was so sick and needed to be in the hospital as her heart was going to give out. It was that bad. Doctors were digging in their heels and refusing to admit her because they didn't want to deal with the patient anymore or didn't think they could. There should never be resistance when somebody is medically unstable. These poor parents are already terrified and depleted and to have medical professionals shrugging their shoulders and saying it's not their responsibility or their bailiwick is just horrible.

The theme, valuing of health care priorities draws attention to professional and systemic issues arising from eating disorder care. Inadequate formal and ongoing professional training, an absence of clearly identified care pathways, and fractures within and between health services leaves health professionals and the individuals they support, vulnerable. Findings from this theme call on the need to fill gaps in knowledge and resources and to address the underlying causes of the fragmentation of care.

Seeing beyond the eating disorder

Within the context of a changing, multi-faceted eating disorder and working in the framework of the New Brunswick health system, health professionals, often in isolation, must determine appropriate action for their patients needing eating disorder care. Seeing beyond the eating disorder is a graduated process characterized by tension, anticipating care needs, taking stock, and mobilizing resources. It is driven by affectivity, and at times moral distress, and culminates in a point of overcoming resistance.

Tension

The transformative process of seeing beyond the eating disorder begins with a sense of tension on the part of the professional. Tension emerges at the intersection of secrecy and physical and mental pain (Figure 1). Individuals affected by eating disorders are “complex” leaving professionals feeling vulnerable. The uneasiness arising from the unknown can be felt by those who work alone as this quote suggests, “What am I going to be able to offer this person?” Or, as members of a treatment team, “If the team doesn’t know the path we’re going on and why we’re doing it, then it can cause a lot of tension.”

Relying on critical thinking, professional skill, and compassion, health professionals can recognize and respond to the physical and mental pain of their patients.

Like any profession, it's about learning how to problem solve, how to listen, and how to communicate. If the patient is sick, when is this situation urgent? What does the patient need?

Anticipating

The tension that first arises gives way to professionals' anticipating a plan of care. Professionals begin to sense that the illness is progressing and are becoming aware that symptoms will not resolve on their own. Professional recognition may exist but with limitations. As one participant said, "I give them what I've got in terms of resources and training." Health professionals begin to consider what resources are available. Symptoms of the illness are appearing but they may not receive priority within the health system. Professionals recognize the precariousness of the situation and will begin to give thought to when and how to get their patient in the 'system.' At a certain point, professionals realize that they will need additional resources and support.

You are problem solving and then when you reach a wall when you've sort of done everything you can, then you need some help.

Taking Stock

Health professionals begin to take stock of existing resources with an aim to mobilize into action. It is at this point that professional's sense of isolation is strongest; Where do I go? Who do I call? This can be challenging when there is no established care

pathway or specialized program. As one participant stated, “We need a go-to list of resources that would take some time away from having to do the research ourselves about what is out there and where we can refer.” Otherwise, as another put it, “I am calling around to know who specializes in eating disorders.”

The ability to consult with specialists who can provide direction has the effect of dampening feelings of isolation. “In the end, I managed to get a specialist on the phone from another province that just answered 10 or 15 questions that I had that I could not answer for the family.” Feelings of existing separately from the health care system can be isolating and distressing for professionals who begin to realize that when it comes to eating disorder care, the system has more gaps than connections.

It was extremely time-consuming trying to advocate for the patient and her family. It was really difficult because it was hard to find help. As the patient’s illness progressed, the resources were really lacking. It was hard to have any justification for the lack of resources for the patient herself but also for the patient’s family, whom I was really involved with. You are talking about a young person who is an adult, but just seventeen. You know, like anybody’s daughter.

Mobilizing

Health professionals begin mobilizing all the while attesting to the toll that the illness is taking on individuals and families. Professionals find it difficult to mobilize when working in a vacuum, “I don’t have a role with other health professionals because usually when I get involved treatment has already begun.”

The mental and physical pain felt by patients is reflected within the health professional and becomes a springboard for that professional to act. These are not ‘clean cut’ processes. Professionals verbalize that “getting a team together can be difficult.” They endeavor to work out a treatment plan but power dynamics can impede progress. Who has admitting privileges? Who is on the team? Who refuses responsibility for treatment? These power dynamics can leave the professional feeling powerless as they search for ways to break the resistance to care. Risking alienation from colleagues, professionals take whatever action is necessary to ensure that their patient receives the care they need.

This physician was calling all over trying to find where this patient could go. So physically, people were saying they can’t take her or don’t want her, while mentally, they were saying, ‘no, you need to do this.’ Somebody has to do something! We can’t lose people between the cracks. This physician did not stop until she found somewhere for her to go.

Affectivity

Affectivity is about being able to put oneself in another person’s shoes. Affectivity contributes to professionals’ capacity to empathize with those whose lives are touched by an eating disorder. Several participants used the word “heartache” and “heart break” to describe the toll on individual lives.

The intensity of caring for someone with an eating disorder can also be “exhausting,” “heavy,” and “very draining” on professionals. In response to their perceived powerlessness, professionals adopt coping strategies to protect themselves

from emotional and professional vulnerability, as one participant stated, “I’ve had to learn to, I can’t even say the word as it is really blunt, to compartmentalize and just walk out the door. And start the day over.” Or, in the words of another participant,

Since then, I’ve learned to draw a line in the sand. Unless a team is put in place and we are all working together, I just can’t ethically go there. All the players need to be lined up. I’ve said to parents that I will provide a service but that they need a doctor who will admit the child. Not that admission is a great thing but sometimes patients need to be in hospital. I think this psychiatrist had no idea how hard it was going to be to get the patient in hospital and her mother didn’t know that this is a really high risk situation. I only know because I’ve been through it with families. And it’s a heartbreak.

Arising from power dynamics and powerlessness are feelings of injustice as professionals’ attempt to cobble together vital resources from a patchwork of services or as they bear witness to families receiving inadequate support or paying out of pocket for necessary medical care.

It’s terrible that families and parents have to pay all this money. If they can’t access it through a provincial program then it should be covered through Medicare if they have to go privately. I just find it too bad. Hopefully someday, maybe there will be coverage for these kids.

When affectivity is met with external resistance, moral distress and moral outrage can develop, prompting professional action. All participants described affectivity, often in the context of a memorable story or event that plagued them.

I really felt strongly and was trying to figure out who to let know that this is not okay. I had another health professional tell me that I was too emotionally attached to this patient. And I wasn't. I think I am a caring person. I'm watching the whole family and I'm thinking, it's really unfair because if it were some doctor's daughter in this community, the patient might have better financial resources to just go somewhere else—but no one I know would watch their daughter go through that and accept the care we had. Nobody would. And the response was that I was caring too much!

Overcoming Resistance

Recognition of the imbalance of power and the moral distress that it causes drives professionals to act. Overcoming resistance is a function of the affectivity and the moral distress and outrage that arises from seeing beyond the eating disorder. As one participant stated, "It's very frustrating to provide care in this province! We know from research that the shorter period of time that they have been sick, the quicker the rehabilitation will be and the better the prognosis."

Through the stories of NB health professionals, the social injustice that stems from the failure of the health system to provide necessary care for an entire group of disorders, and consequently, the effect that this decision has on the lives of those affected becomes clear.

How do we have a community where we've just accepted that we don't deal with it? Why are eating disorders different than any other medical issues that are in front of us? Why is it okay not to have a plan? Why is it okay that we have that in

every other area but we accept that we're just going to let these people with eating disorders float around and some are going to spend money in private clinics so they won't be our responsibility?

Chapter Summary

As this collective story illustrates, use of narrative inquiry was shown to be a safe approach to enable participants to dialogue about their experiences in caring for persons affected by eating disorders. Inviting health professionals to share their experiences in eating disorder care revealed challenges related to the nature of eating disorders and to the shortcomings of the health system itself. Professionals' experiences in providing support and care to individuals affected by eating disorders, enabled them to see beyond the manifestations of the eating disorder to the individual and families whose lives are often dominated by the illness. Findings demonstrate a need to ensure that necessary resources are in place to guide professional intervention and optimize care.

Chapter 6: Discussion

Seeing beyond the eating disorder challenges professionals to look beyond the obvious by considering the unspoken subtexts and conditions that impede identification and treatment of eating disorders. The process of seeing beyond the eating disorder requires deeper reflection of the characteristics of eating disorders and the systemic conditions that affect care. Eating disorders are complex, potentially life threatening brain based illnesses. Through examination of health professionals' stories, we advance understanding of how professionals conceptualize eating disorder recovery and provision of health care, as well as increase awareness of professional knowledge and practice needs.

For health professionals, the puzzling nature and prevailing secrecy of eating disorders challenges professional recognition and early intervention. Consistent with other research, results of this study support the view that secrecy, complexity, and stigma play a role in early detection and treatment of eating disorders (Banas et al., 2013; Bannatyne & Stapleton, 2015; Trent et al., 2013). Findings make aware that professionals cannot rely on outward appearance to determine the presence of an eating disorder or disordered eating. Additionally, results of this study affirm that the occurrence of eating disorders is not restricted to youth and young women. As results indicate, eating disorders affect both genders as well as a wide age range. Moreover, families play an important role in detection and intervention for those affected by eating disorders. As evidenced by the study results, eating disorders have a profound physical, emotional and financial toll on families. It is therefore imperative to address the needs of families,

including providing education, support, and resources to enable families to share in eating disorder care.

Limited professional socialization hinders professional ability to respond and intervene in eating disorder care. Consistent with other studies (Banas et al., 2013; Hughes et al., 2014), eating disorder training was a frequently cited gap among health professionals. The present study also highlights that, in the absence of opportunities for formal professional development, professionals will rely on less optimal ways to increase understanding of eating disorders and treatment interventions. Although, incidence of eating disorders is relatively uncommon when compared with mental illness such as major depression and anxiety disorders, generalist health professionals can still be confronted with incidences of eating disorders, requiring some knowledge of detection, treatment options, and resources. Further, as most patients will return to the care of primary health professionals, mental health therapists, and private health practitioners, consideration must be paid to ensuring that these professionals remain a part of the circle of care to facilitate transitions.

This study's findings are consistent with other research findings that highlight the need for an interdisciplinary approach to care (Health et al., 2013; Hughes et al., 2014; Linville et al., 2010; Pinzon et al., 2013; Raveneau et al., 2014). As with other eating disorder research by Banas et al. (2013) and LaFrance Robinson et al. (2013), findings in this study support the need for early intervention. Further, results suggest that having the ability to consult with professionals who specialize in eating disorders can help to reduce professional isolation and feelings of vulnerability for those with limited eating disorder training and experience and can help to inform early intervention and treatment options.

This study contributes to our knowledge of eating disorders by making visible the effect of power dynamics in eating disorder care on individuals, families, and health care providers. As results show, the persistent divide between physical health and mental health care continues to negatively affect eating disorder care. Consequently, health care priorities and professional socialization impede professionals' ability to connect individuals affected by eating disorders to necessary care. Fragmentation of services and gaps in care further challenge professional response.

One of the most striking findings of the study is the occurrence of moral distress among health professionals working in eating disorder care. Moral distress refers to health professionals' experiences of "frustration and failure arising from struggles to fulfill their moral obligations to patients, families, and the public" (Austin, 2012, p. 28). Distinguishable from moral dilemmas that are characterized by not knowing the right thing to do, moral distress involves knowing the right course of action but feeling professionally constrained to act (Austin, Bergum & Goldberg, 2003). Awareness and acceptance of moral responsibility and obligation are key elements of moral distress (Austin, Bergum, Kagan & Lemermeyer, 2005). Distress arises when one course of action is considered morally superior but for reasons beyond individual professional's capacity, the ability to pursue that course of action is impeded (Weinberg, 2009). Moral distress results from failure to maintain professional standards of care and is brought about by the disconnect between professional responsibility and the power to act (Austin, 2012). Triggers of moral distress include institutional regulations limiting professional practice, inability to influence decisions in the face of patient distress, and lack of recognition for professional expertise within established power structures (Austin, 2012).

The outcome of moral distress and outrage identified in this study matches other studies' findings of health professionals' response to being asked to do too much with too little (Austin et al., 2003). As these findings reveal, health practitioners working in eating disorder care experience moral distress when responsibility to provide care is acknowledged but ability to respond or to make the right decision is thwarted by systemic constraints. Consistent with other research on moral distress (Austin et al., 2003), findings from this study reinforce the understanding that frustration, anger, and helplessness arise when professional responsibility to act is stymied by systemic constraints. The significance of these findings cannot be understated as unresolved moral distress can affect professionals physically, emotionally, and spiritually and can lead to "burn out" and leaving one's profession (Austin et al., 2005). Thus, it is recommended that future administrative focus should not be limited to professional training in understanding, identifying, and treating eating disorders but must also address the underlying systemic issues that restrict health professionals' ability to adequately respond to the needs of individuals affected by eating disorders.

Policy Implications

Having discussed the scholarly implications in the previous section, I will focus here on the implications for policy. First, findings in this thesis are a call to action, as they highlight what is needed in terms of eating disorder care in New Brunswick. Development of a New Brunswick plan of action for eating disorder care would align with a recent federal motion calling for the development of a coordinated Canadian strategy on eating disorders. Ideally, New Brunswick policy guidelines would involve a

three-pronged approach including prevention and early intervention strategies; specialized community based and in-patient treatment; and program monitoring, evaluation, and research. Guidelines should encompass best practice and should be developed in consultation with subject matter experts and NB health professionals.

As findings suggest, our fragmented approach to eating disorder care is both contrary to best practice and to the desires of health professionals who are providing eating disorder intervention and treatment. Therefore, the first area of focus should be on the development of a care pathway for eating disorders. Primary care practitioners play a key role in screening, early intervention, treatment, and consultation with specialists. As the lynchpins of primary care, doctors and nurse practitioners need training on screening and identification of eating disorders, and a list of available resources to guide intervention. Further, we need to develop alliances between the medical and dental community and encourage development of oral practitioners' role in identification, secondary prevention, and referral to medical colleagues and mental health providers.

A review of current guideline documents governing interdisciplinary inpatient treatment for medical stabilization is needed with an eye to ensure that they reflect current best practice, are patient centered, and consider individual developmental stage and need for family involvement. Community based intervention must be reviewed with an aim to develop stronger therapeutic alliances and treatment teams that are interdisciplinary in scope. As schools are a natural setting for prevention and early detection, consideration should be given to how eating disorder care fits with the newly adopted integrated service delivery model being rolled out in the province. This may

include specialized training for educators and professionals working as part of the mental health clusters.

Lastly, opportunities exist to partner with the university on program evaluation and research. This effort would include involvement by the faculties of nursing, education, kinesiology, psychology, and social work to inform best practice interventions. Further, using administrative data available at New Brunswick Institute for Data, Training, and Research can assist with monitoring the prevalence and incidence of eating disorders in New Brunswick thus assisting with determining adequate allocation of services.

Suggestions for Future Research

As health care priorities and professional socialization are shown to have a profound effect on eating disorder care, results of this study suggest the need for further exploration on the effect of power as a barrier to effectively responding to the needs of those affected by eating disorders. Including the experiences of individuals who have accessed eating disorder care in New Brunswick would elevate understanding.

Limitations of Study

These findings represent the experiences of eight different health professionals, all of whom had some experience working with individuals in the province of New Brunswick. Although the research sample reflected every health profession typically involved in eating disorder care, sample size was relatively small as only one or two members of each of the seven disciplines were recruited. Despite the small sample size, it was still adequate to identify themes. Further, the aim of the study was to consider

participants as a group rather than to differentiate by discipline, as dictated by the study design.

Although efforts were made to gather data from various parts of the province, participants primarily represented the larger geographic regions and are not representative of all zones within the Anglophone managed regional health authority. Language limitations necessitated restricting of data to English language populations. As the only officially bilingual province, with two distinct linguistic regional health authorities, findings cannot be assumed to reflect the distinctive experiences of francophone health professionals or the francophone managed regional health authority. Future research studies may want to examine all regions to determine if the needs and experiences of health professionals differ between regions of the same Regional Health Authority.

Dissemination of Findings

Research findings are reported as an aggregate to decrease discrimination of individual professions. Research results will be disseminated within this Master thesis and then in scholarly, health and general communities via peer-reviewed and lay journals and public presentations. Preliminary findings were presented at UNB Faculty of Nursing 21st annual peer reviewed research conference (May 2016) entitled Moving Research to Policy and Beyond (Appendix G).

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Appendix A: Recruitment Poster

**Are you a health care provider who has worked with persons with eating disorders?
Are you interested in participating in a study about health professionals’
experiences with eating disorders in Atlantic Canada?**



You can participate if you:

- Are a health professional in one of the following fields: medicine, nursing, occupational therapy, psychology, dentistry, social work and dietetics
 - Have worked individuals with eating disorders in Atlantic Canada
 - Are willing to participant in a telephone or face-to-face interview
- If you want to assist in this important research, please contact the research team
University of New Brunswick (506) 451-5045 or email twilson@unb.ca**

Eating Study (506) 451-5045								
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Appendix B: Qualitative Information Letter



- Title of Project:** Health Professionals Perspectives of Eating Disorders Across Atlantic Canada
- Principal Investigator (PI):** Dr. Kate Weaver, Associate Professor, Faculty of Nursing, University of New Brunswick, (506) 458-7648, kweaver@unb.ca
- Research Assistants (RAs)** Tanya Wilson, BSW, Master's Student
Samantha Braman, BN Student
- Purpose:** To study the perceptions of health professionals who care for persons with eating disorders in Atlantic Canada. The research will help understand the needs of those with eating disorders and those who care for them and will provide insight into potential treatment and research initiatives.
- Background:** You learned about this research from an advertisement or from someone already participating. You are invited to participate in an interview. We will ask you to share your experiences, perceptions and knowledge of eating disorders as a healthcare provider.
- Expectations:** The interview will be conducted by one of the research assistants (RAs) in person or by phone. The RA will ask you to talk about your experience with eating disorders as a healthcare provider. The interview will take 30 – 60 minutes, be audio recorded and transcribed. All identifying information such as names and places will be removed. Only the RA who

interviewed you will listen to your interview. The written record (with identifying information removed) will be read by the research team of RAs and principle investigator. If you wish, you will receive a copy of your written transcript and account of your interview. In addition, you will be offered a summary which includes information from other healthcare providers who participated in the study. This summary will not contain any names or identifying information. You will have the opportunity to comment on the written accounts.

Benefit:

There may be no direct benefit to you for participating. However, you may appreciate sharing your experience and knowledge about eating disorders in Atlantic Canada.

Risks:

There are no expected risks in participating. You might possibly experience unsettling emotional responses or want additional information about eating disorders. A list of resources, including contact information for local helping agencies, eating disorder resources, the research assistants, and the principal investigator will be provided to you if you wish to seek future information. Throughout the interview the RA will provide sensitive care. Should you become upset, she will stop the tape and you will have the time to decide if you wish to continue.

Confidentiality:

Any identifying information will be removed from interview transcripts. No real names and places will be used in any report about the project. No identifying information will be used in any publication. Only the RA who interviewed you will know your identity.

Any Future Use of Information:

All collected information will be stored in a locked cabinet in the RA's office throughout the study. After the analysis is complete, data will be transferred to a secure, locked cabinet in

Dr. Weaver's office. The signed Consent forms will be stored separately from the research information. These data will be retained for a period of seven years following completion of the study. The anonymized written reports are restricted to Dr. Weaver and the RAs who will be involved in analyzing the reports from which all names and other identifying information have been removed. The RAs will be held at the same level of confidentiality as Dr. Weaver. No names will be used in any discussions about the interview information.

Dr. Weaver will keep one copy of the transcribed interviews with identifying information removed.

**Freedom to
withdraw:**

You are free to withdraw your consent to participate at any time during and following the interview. There will be no negative consequences to you if you choose to withdraw.

**Right to refuse to
answer a question:**

You are free to not answer any question.

**Informed About
Study Outcome:**

If you choose to participate in the interview, you will receive a copy of your written transcript, an account of your interview, and a summary of the research findings. It will be sent if you wish by e-mail or Canada Post.

**Additional Contact
Information:**

If you have any concerns about any aspect of this study, you may contact the following people who are not directly involved: Dr. Kathy Wilson, Assistant Dean of Research and Faculty Development, UNB Faculty of Nursing, (506) 458-7640, e-mail: kewilson@unb.ca or Steven Turner, Chair, UNB Research Ethics Board, (506) 453-5189, e-mail: turner@unb.ca.

Appendix C: Informed Consent for Participants in an Interview



Health Professionals' Perspectives of Eating Disorders in Atlantic Canada

PARTICIPANT QUESTIONS	
1. Has this study been explained to you?	Yes <input type="checkbox"/> No <input type="checkbox"/>
2. Have you read or had read to you a copy of this consent form?	Yes <input type="checkbox"/> No <input type="checkbox"/>
3. Have you had an opportunity to ask questions & discuss this study?	Yes <input type="checkbox"/> No <input type="checkbox"/>
4. Do you understand the information that has been provided?	Yes <input type="checkbox"/> No <input type="checkbox"/>
5. Do you understand that you are free to not participate in one or more parts of the study?	Yes <input type="checkbox"/> No <input type="checkbox"/>
6. Do you understand that you can withdraw from this study at any time without consequences?	Yes <input type="checkbox"/> No <input type="checkbox"/>
7. Do you understand who has access to your personal data?	Yes <input type="checkbox"/> No <input type="checkbox"/>
8. Do you understand that you will receive a signed copy of this consent?	Yes <input type="checkbox"/> No <input type="checkbox"/>

PARTICIPANT STATEMENT

I have read the above information and understand the purpose of this research as well as the potential benefits and risks of participation. I have had the opportunity to ask questions, and my questions have been answered. I have received a copy of the consent form, and I give permission for the information I provide in the interview to be used for the purposes of this research. My signature confirms that I hereby give my informed consent to be a participant in this study. In lieu of my signature, the research assistant will complete the consent form through verbal discussion with me and my verbal

acknowledgement of consent (stating: “I consent to participate in this study”) on tape will suffice as appropriate consent to participate.

I wish to receive a copy of the transcript from my individual interview. Yes No

I wish to receive a summary of themes identified in the interviews. Yes No

I wish to receive a summary of the completed research. Yes No

I wish to be invited to a presentation of the research findings. Yes No

I wish to be notified of any future research project that will be planned based on the findings from this study and to have the opportunity to ask questions about it. Yes No

If yes to any of the above, how do you prefer to be contacted? Please give your contact information (e.g., email or mailing address, telephone number):

Email _____ Telephone _____

Postal _____

Printed Name of Participant

Signature of Participant

Date

Printed name of Witness

Signature of Witness

Date

Researcher Statement

RESEARCHER STATEMENT

I have explained to the above participant as appropriate the nature, requirements and the purpose of the study, potential benefits, and possible risks associated with participation in this study. I have answered any questions that have been raised. I believe that the participant understands the implications and the voluntary nature of the study. If signed consent cannot be obtained either due to the participants' inability or not wanting to sign a consent form but still wishing to consent to participate, completion of the consent form by the research assistant through verbal discussion with the participant and participant's verbal acknowledgement of consent (stating: "I consent to participate in this study") on tape will suffice as appropriate consent to participate.

Researcher (Print)

Signature

Date

Appendix D: Interview Schedule

Interview questions are outlined below. It is not necessary to ask questions beyond the introductory question. However, it is critical to clarify understanding of the participant's responses during the interview. Questions 2-6 provide a guide for future clarification.

Introductory Questions:

- 1) Tell me about your experience of being a healthcare provider working with persons affected by eating disorders
- 2) Tell me about your perceptions of eating disorders and your feelings about persons presenting with eating disorders and their families.
3. Tell me how the care and services you provide potentially influence recovery from eating disorders.
- 4) Tell me your knowledge level of eating disorders.

Clarifying questions:

- 5) How have you treated individuals with eating disorders in the past?
- 6) What do you feel are barriers to you in terms of treating an individual with an eating disorder?
- 7) What do you feel has caused you to perceive eating disorder in such a way?
- 8) What do you need in order to best support an individual with an eating disorder?
- 9) Is there anything you wish to add?

Appendix E: Core Stories

Participant 01

In my dental practice, I haven't had a whole lot of experience with eating disorders. In dentistry, we were taught some information but it was a quick run-through; here's the acid erosion, here's the primary causes, gastric reflux being the usual, and then bulimia and other eating disorders and then other causes for dissolving teeth. I honestly have my doubts if much information about eating disorders is being taught in dentistry today. Dentistry is spinning more and more to high tech, more expensive equipment and more expensive techniques. It's easier for the dentist but they don't necessarily do a better job. Then, when dentists get into a tough situation, they can't manage because those high tech things won't help you. In order to become a dentist, doctor, anything these days, you've got to be so academically inclined that you can't be human.

I have never been involved in a direct diagnosis of an eating disorder. They may be my patients or they may show up as a referral. I don't have a role with other health professionals because usually when I get involved, treatment has already begun. All the patients that I have ever seen have been young females, around age 18 or 19. Most of them have a parent around and I've got the challenge of confidentiality. I have to watch my approach. I usually sort of quiz a little bit, bouncing the skirts of it, to see what I can find out without actually talking about it. If I am more direct, their first response is to say they have gastric reflux because they have learned from reading or whatever to respond that way. I have learned to watch the body language and facial expressions and have tried

to make it a 'non-approach' in order to find out more information and to open the door. It is challenging because I already have somebody who is defensive.

Most of the patients that I have suspected were already being treated for gastric reflux. That's the challenge. It can look very much the same. I assume that it is. After all, they are being treated for gastric reflux, so therefore that must be the cause. I am kind of caught. I don't want to push in a different direction if my patient is already being treated for something else.

Denial is their primary response. That is why I don't suggest an eating disorder because that is automatically shut down and it's not going to go any further. If I can skirt around it, sort of figure it out, assuming that that is what it is, then I'll push the stomach issue with parents. Usually I get the parents involved by quizzing and asking and assessing and showing the damage to the dissolving teeth. And usually at that point, I'll give them a way out because the parents don't know. I won't say eating disorder because that just panics everybody. So I say, 'Ok, look the teeth are being dissolved and there is obviously something wrong'. By suggesting it's a stomach issue and using the teeth as a rationale, I advise parents to get her to see the doctor without labeling it an eating disorder because that kid's going to rebel right away.

A dentist's role is in the diagnosis and the treatment of the damage. With bulimia, as with gastric reflux, it's localized more to the anterior top teeth on the backside. There is generally malnutrition built into eating disorders so the gums are not as healthy as they should be. The teeth usually are spotless because they have been acid washed so as a dentist things don't make sense. They don't tie together. It's the incongruence. There are certain things the body does that sort of jump out as being off.

It is usually bulimia that I have treated directly and the gastric reflux problems that coincide with the disorder. Most of my experience has been involved in trying to deal with the damage that has been done to the teeth. Usually, the first area of damage occurs on the backside of the top front teeth as the teeth are actually being dissolved.

If I catch it early enough then it's not anything I would actually treat. In these instances, my role is more preventative, trying to educate patients about fluoride and diet and getting away from the acid in order to protect and maintain their teeth. The sensitivity is already there. And the system is so used to being sick all the time, trying to keep all the acid content down. The teeth are already so vulnerable that it is not going to take much to progress to decay and then fractures.

With eating disorders, dentists are not really involved with other professionals in the treatment of the patient. I'm not going to see that patient again for six months or a year. I need consent to communicate. And generally my experience is that doctors aren't good at sharing. That's their protected turf. But it's not their turf. It's the patient. I find things out by talking and listening. And sometimes doctors didn't find out because they didn't bother to look and listen with their ears. Sometimes parents will come back and report that she is now taking supplements and she has been getting counseling and help. And other times, I don't know what the physician does. Sometimes I never know because the patient is mad at me for telling.

I have one patient in particular, who has extra problems on top of her eating disorder. She is malnourished, underweight, and an extreme chain smoker. I couldn't go in the room with her as it smelled so bad. Her teeth are being dissolved. We have talked about it. She knows about it. She is being treated for gastric reflux but it is obviously not

just gastric reflux. It's anorexia. I don't know whether they are dealing with the situation. Her mother seems to support it. It doesn't sound like they are dealing with it. My patient admits that she does it but as far as doing anything about it—I don't know what I could do. She is so set. You know, 'I have a problem but I'm not going to change'. You can't help people if they don't want to be helped. That is the frustrating part. Yes, this is just what it is. She can't fight anything and is sick all the time. She is going to kill herself. It's just a matter of how it will happen. I have been waiting for her to die. And the hardest part is that I have seen her as a child. Watched it progress. And now she is in her 20's. It's frustrating. I've had to learn to, I can't even say the word as it is really blunt, to compartmentalize and just walk out the door. And start the day over.

Participant 02

I have worked in the area of child and adolescent mental health for thirteen years. The files that stand out as extremely challenging are those patients diagnosed with anorexia nervosa. Their mortality rate is the highest. Their risk of dying is more than our other clients. The medical complications are something separate from what is provided in community mental health. I end up being consulted a lot because of my nursing background. Some psychiatrists want my involvement to take weights and to talk about the physical aspects of the diagnosis.

Eating disorder training has always been number one on our list. Although we ask, there is not a lot of training. There is also the issue of funding. I can't remember the last time we had *good* training and then we have to draw straws to see who gets to go. Which is

kind of bizarre when you think about it. Our team is randomly assigned files so we all have experience working with eating disorders. Yet, only some of us will have training. We've had conversations about becoming specialized and most would be agreeable but we shy away because we aren't 100% convinced that we would receive support for training. We are afraid that we will be put in situations where we are asked to provide a service. Then, the next thing we know, we are part of a team that doesn't have training and we are in over our heads.

You definitely want to get ahold of eating disorders in the first two years. I have worked with some youth that are three plus years in their disordered eating patterns. At that point, behaviors are so entrenched, and families so depleted, that it makes it really difficult to do outpatient therapy. Best practice is the Maudsley approach. I learned a lot from co-therapy with a psychiatrist. We used Maudsley with one youth who probably had disordered eating for about a year. We met weekly with her and her parents. It was definitely effective. But my heavens, these families need to be ready and able to do the work. The Maudsley approach is beautiful, in theory. But a lot of our parents are so depleted that they are seeking services for themselves, marriages are breaking down, and siblings are being neglected. People need so much support. It's just awful. It's complex because there are a lot of issues that need medical follow up and intensive resources. It always surprises me that parents don't bring kids in earlier. Families don't recognize it as much as medical practitioners, perhaps. Sometimes youth come for secondary issues and we need to backtrack. Yes, your daughter has anxiety, *but* they also are very, very underweight. I'll suggest that they see a doctor to be weighed and to check BMI. I've had a handful of families come back saying that the physician had no concerns. I have even

had doctors admit that a patient is pretty thin but it's just dismissed. And I think, 'wow' we need to address this now. It's kind of like the elephant in the room. If we can catch this earlier, we're way ahead of the game. Once a behavior has been entrenched for two plus years, it is so complicated at that point, to turn it around.

I don't think we've ever had a school refer anyone for an eating disorder. Usually, it's a family member, pediatrician, or medical practitioner. Some pediatricians are awesome and totally get it, while some GP's and pediatricians will shy away. Some pediatricians openly state that it is more of a mental health issue and it's just not something they feel specialized in. For some reason, some family practitioners don't see it as concerning as we do. Maybe they don't know the importance of catching this early. We don't want youth in hospital for months and months at a time. I'm not saying that's a horrible thing because sometimes it's needed. I have worked with families who are so overwhelmed and have been dealing with this diagnosis for such a long time that we had to pay for service providers to go in to the home and help them take care of their child.

The challenge working with patients with eating disorders at the community level is the dispute over who should follow the file. Should it be the medical practitioner? For children and youth that would be the pediatrician. Or should it be the psychiatrist? We have difficulty educating health professionals that a combination of both psychiatric and medical follow up is needed. Some patients are on SSRI's if they're anxious or what not, so we need psychiatry. We also desperately need the medical piece and we have not received that with these files. We need a team approach with eating disorders. We can't just have a silo approach. When pediatricians and psychiatrists are working together and a weight protocol is in place and patients know that they may have to go into hospital, not

for a long stint but for a short period of time to get to a healthy weight; it works really beautifully. With all the players involved, we've provided a good service and kept youth out of hospital.

I have always had very good experiences working with dietitians. Dietitians are just so important for developing appropriate, realistic eating plans. I'd never pretend to know more than a dietitian about what patients need to be eating on a regular basis to either sustain their weight or get to a healthy BMI. I will namedrop to parents to suggest that they ask for a certain person because that person knows what they are doing. We have some excellent dietitians in private practice, in hospital, and through Extra Mural.

Once eating disorders are entrenched, we are in big trouble. I had a sixteen-year-old client who was tube fed for a while, she was so ill. Those files are really difficult. And when they do go into hospital for months at a time, there is no treatment. They are just getting medically stable to get back into the community where they get their treatment. She spent months as an inpatient. She was medically stable when discharged but had received no treatment. I'm not trying to dismiss what they do in hospital. I'm sure the social workers and psychologists check in. But, I wouldn't consider that evidence based treatment.

When youth are really, really sick, we can't do therapy with them because their brains aren't functioning. We don't have inpatient treatment in New Brunswick. In order to be admitted to some out of province treatment centers, patients have to be physically stable, have a certain BMI, and full medical clearance. The rationale is that they need to be well enough for treatment. We did get the 16-year-old up to the BMI required for out of province treatment but in the end, she decided not to go. I look back and think, wow, if

she had spent those months in hospital receiving treatment for her anorexia that would have been really beneficial. That's a pretty huge gap in our system.

I certainly learned a lot about the system, and barriers to services by working on one very high profile, complex eating disorder file. What definitely stands out is this pointing match of who is supposed to be working on the file. There ends up being this divide with medical practitioners and hospital and community mental health. One young girl was so sick and needed to be in the hospital as her heart was going to give out; it was that bad. Doctors were digging in their heels and refusing to admit her because they didn't want to deal with the patient anymore or didn't think they could. That has been troublesome for us. Hospitals and doctors need to be willing to admit to paediatrics. It may be a lack of training or a belief that it is strictly a mental health responsibility. Yes, it's a community mental health file but the clinic is only open 8:30 to 4:30. We know how the illness works. At times, youth need inpatient admission and we all need to be working together, especially when they are that ill. We need a dietitian, a psychiatrist, a therapist, and maybe another therapist to do the family piece. These are huge, huge files. We can't work in separate silos.

We know what the health system is like, once someone is medically stable, they are going to go home but are still very ill. Their eating disorder is still very prominent. Then, parents are involved 24 hours, providing supervision, treatment, and all the monitoring of food. Basically, parents are providing hospital care to a child at home. For this young girl's family, it was difficult to be consistent with the re-feeding at home. It can get pretty volatile sometimes. This youth was fighting with her parents. She was so ill, so resistant, and oppositional. But that's the eating disorder, that's not her. She was

really, really sick. In fact, she almost died twice while under my care. Through regional complex case, we got the necessary funding to hire non-professionals through a private agency to help the parents in the home because this family was falling apart. I was probably at that home twice a day for the first two weeks, training workers and showing them what to do. That's way out of the scope of what I'm supposed to be doing and it isn't ideal. The patient really should have been staying in hospital. But what do you do? We were just doing the best that we could. The hospital closed their doors to her and we had to do that to keep her alive.

Since then, I've learned to draw a line in the sand. Unless a team is put in place and we are all working together, I just can't ethically go there. All the players need to be lined up. I've said to parents that I will provide a service but they need a doctor that will admit the child. Not that admission is a great thing but sometimes patients need to be in hospital. I once told a referring psychiatrist that the youth needed a paediatrician and a dietitian before I would even start therapy. This psychiatrist didn't have admitting privileges and the youth didn't have a pediatrician or even a family doctor. I thought to myself, how are you going to get this youth on paed, if God forbid, something happens to her medically? This is a ticking time bomb. I think this particular psychiatrist had no idea how hard it was going to be to get the patient in hospital and her mother didn't know that this is a really high-risk situation. I only know because I've been through it with families. And it's a heartbreak. These poor parents are already terrified and depleted and to have medical professionals shrugging their shoulders and saying that it's not their responsibility or their bailiwick is just horrible. In this situation, it all fell into place eventually.

The way to keep patients out of the hospital is to catch them early and provide treatment. We know that's just a dream. Sometimes that doesn't happen. So, we need to know that patients can get the necessary medical follow up, without any barriers or a wait. They shouldn't be locking the doors on pediatrics, saying this is a community mental health issue. It's shocking for me to say that, but it's true. We have had that happen and have involved ethics. There should never be resistance when somebody is medically unstable. It's not that mental health needs to be doing a better job to prevent admission. It doesn't work that way. Sometimes patients are going to have to be admitted. Unfortunately, it's just the nature of the disorder. They are complex files and such scary medical issues. If you are all alone, eating disorder files can be really frightening for some clinicians. I would like to know that if I had a youth walk in my office with a suspected eating disorder or I received a referral for a youth diagnosed with an eating disorder or disordered eating behaviors, that I can pick up my phone and bang-- we're all connected. That no one is alone. That would make life so much easier.

Participant 03

I worked as a social worker on a paediatric unit for approximately 7 years. We didn't really see bulimia but youth were admitted with anorexia because they were actually starved to the point that they were experiencing some scary symptoms. We got between 5 and 8 patients with eating disorders per year. At times, we would have 3 or 4

patients and one time, we had 5 or 6 patients at once. Again, that was more of an exception but it was really hard to give good service.

Paeditricians try to keep patients out of hospital for as long as possible and will do tele-health before patients are admitted. Sometimes patients were admitted directly because something medically was going on. Patients were admitted under a standardized contract. It was very controlled at first, with almost 100% bed rest. Patients are really under the control of the illness and are not able to think straight or make decisions in their best interest. The multidisciplinary team met weekly to go over the contract with the family. If patients either weren't able to manage completing their meals or did not gain weight, then usually they needed more bed rest and very little energy expenditure. Sometimes they couldn't even walk to the bathroom. They needed to use a wheelchair. If their health improved, again depending on their heart rates, then maybe they could have a tiny bit of activity.

Trying to find consistency among the team members was challenging. There would be a lot of mixed messages and a lot time spent on interpreting the contract. Nurses would sometimes disagree about how to do things and that affects the patient directly. Nurses didn't have training about meal support and they were getting frustrated. Everybody is frustrated. Parents would complain to me a lot. Meal support took a lot of resources because nurses had to sit for every snack, every meal, and a certain amount of supervision after each meal and snack so you just felt the stress from the family, the child, and the whole unit. Again, it's not that there is any body to blame. It was such a resource, even for me. I would try to meet the patient a couple of times a week, meet the

parents every week, and attend the family meetings. When you've got a lot of patients, it's very intensive that way. It just felt so heavy.

The dietitian decides what patients are eating and how much. The child would have some decision-making but they couldn't decide how much went on their plate or whether they could have protein. It was all very structured, pre-planned and pre-decided. At first, parents remove themselves from meal support for a couple of reasons. The parents are burnt out. They are *soooo* tired of trying to get their child to eat and their child won't eat. By the time the child is admitted, parents are a mess. Understandably. So, this gives parents a break from that whole dynamic. As the weeks go on, parents are more involved and are in charge of implementing these strategies at home. Parents from rural communities would either stay in town, room-in, or would travel back and forth. Depending on the situation, there would be regular outpatient appointments to keep monitoring how things were going after discharge. Every situation would be different but the hospital team was really open to staying involved after discharge.

It's a big process to get from admission to discharge. Patients were very time-consuming. From early on, we would think about discharge. Initially, we were doing the discharge planning a bit late and supports were not quite in place. The other challenge was finding counsellors in the community with an expertise or availability. Most families ended up going private and some had private medical coverage. If families didn't have coverage or wanted the mental health clinic, then we would get them involved so that the rapport could start being built. We didn't want them necessarily doing the counseling in hospital because they are not part of the hospital team and not necessarily able to make all the meetings, and our psychologist was already involved. Patients would have a team

in hospital but to make that follow through in the community was sometimes hard. It was hard to find good resources and to come up with a really comprehensive plan as an outpatient.

Sometimes things would fall apart at home and patients would need to be re-admitted. Then, I would try to understand the intricate details about what was happening and how were meals structured. It gets difficult when parents don't follow through. And there may be good reasons considering how challenging it can be. It's not even a parent's fault. Parents do their absolute best but this is an eating disorder. I would interpret it like, what other supports do we need to put in place and what more education might be needed.

When it happens that the child is losing weight repeatedly and there are other family issues, we question if we should be calling child protection. There is a clause in the Family Services Act; the child is beyond control. There was one extreme situation where we had to involve child protection because her behaviors were so challenging and the parents were unable to do it. I remember mental health, child protection and the hospital all worked together to get mega services in the home to support the meal structure. I don't always know the outcomes after discharge. But in this situation the outcomes could have been really different without those supports in place.

It's important as a pediatric team to present as a united front. Roles are so important because it's easy to sabotage. It would be easy for the dietitian to say, 'no, this is what you're eating' and I would be trying to 'advocate' for the patient to make more of her own choices. But that would not have been the right thing to do and would have

caused more trouble. At first, I probably did some of that, until I realized, wait a minute, I don't really know what I'm doing. I need to do my research.

My primary role was to provide support to the parents and family. I would show them videos about how to model meal support. My role with patients was talking about communication with family, or self-esteem and body image. Psychology did the one-to-one coping strategies. Psychology, the dietitian, occupational therapist and I would always consult about who was doing what piece of work. I had to learn by myself along the way. I did go to one or two eating disorder conferences but only some parts pertained to my paediatric work.

Sometimes I would be stuck and would consult professionals in another city or out of province. Parents would ask me things like whether to give the same portion of food to their other kids, and I'd be thinking, I don't know. I did a lot of consulting with a social worker from an out of province eating disorder team. One case was so complicated and so scary that I would consult because there was no one here. She shared a lot of resources and I felt like I was getting more of that 1 to 1 connect because we played the same role, working in a hospital setting with a multi-disciplinary team. The mental health clinic also sees people with eating disorders but things are different with outpatients. Without the support and resources, I would have not known the importance of meal structure and probably would have left a lot more of the control to the patient. As social workers, we think that the more control you can give a person, the better, because they are the experts of their life.

Patients admitted with eating disorders just felt more complex, maybe because they would stay for two or three months at a time which for paediatrics is a long

admission. What I found challenging is that it involves food. As parents, your instinct is feed your child, to take care of, and nurture your child. And when parents can't do that, it's actual torture and suffering on the parent. I don't think there was one parent that didn't say, why didn't I notice, or do something sooner, or clue in. There wasn't a single parent that didn't blame himself or herself and ask why they were not able to feed their child. There is something about not being able to feed your child that does something to parents. And, parents' level of exhaustion was obvious.

Parents that really had a loving, yet very structured, assertive, and disciplined parenting approach, probably did better because they were able to withstand the child's resistance and behavior and the kids knew that parents had their limit. For families with other stressors and whose life was more chaotic, it seemed way more difficult to implement structure. I would tend to see those families with more re-admissions. Even when parents did everything right, there was still no proof or guarantee. Nothing is. But there was definitely more struggle with the families with other issues.

One mother was amazing! From the beginning, she was the one who noticed her daughter's changes and went to the doctor to advocate for her. There was just no messing with this eating disorder. This mom had such a fierce approach to the eating disorder. She was able to separate her daughter from the disorder but had very clear boundaries. This mom had experience from a personal perspective so she had gained her own knowledge of it in a different way. She knew the signs. Having that education seemed to provide that extra advantage.

With all the disorders and issues, I cannot say that eating disorders training is specifically needed in social work schools but there definitely has to be training if you end up

working with patients with eating disorders. It would be interesting to see what that would look like in a social work school. It would have to be someone who is specialized in eating disorders, not just mental health, and to make sure that it's based on best practice. Because again, they may teach things like, you need to empower the patient.

More training is required for everyone. I think in some ways, we all felt like we were walking in the dark. It is such a debilitating disease. And, their lives are in your hands. If the team isn't working well together, and don't really know the path we're going on, and why we're doing it, then it can cause a lot of tension. We needed training so that everybody was on the same page. As time went on, I think we got better at it but I don't think it was optimal. And I think it could be a lot better. If there could be some way of getting formal training about the most recent research based model. I've heard some health professionals even say things like, you just need to eat right, or you just need to eat like a normal person, comments like that. It's not that they're ill intentioned. It's just that sometimes you need to have education about what actually an eating disorder is. Without that, you're walking in the dark.

Participant 04

I have many college and university age patients. I have found that more and more, patients are presenting with anxiety, depression, and other mental illness. I find young people are very hesitant to talk about eating disorders. It's really hard for them to disclose when they're struggling with an eating disorder. They have a hard time naming it. When I

notice red flags, I try to bring it up but they deny or do not want to talk about it. So my experience has been sporadic.

In my undergraduate nursing degree and my Master's program, there was not a lot about eating disorders. We haven't had any specific training on eating disorders at our clinic. So, it's a struggle. I get patients who are very complex and I'm thinking, what am I going to be able to offer to this person. So I'm doing my own research and trying to collaborate with colleagues who may have more experience. I do the best that I can to help them and to give them what I've got in terms of resources and training. It just seems with eating disorders, it's so hard to change the patient's self-perception. You can put all the resources into helping that person but ultimately the person has to find it within to make that change and to be able to commit to the follow up. It's a lifelong thing.

For me, it's been women who have presented with eating disorders. Actually, athletes are a whole other kettle of fish. Trying to make certain weight classes, say for wrestling, they really, really restrict themselves. And so I see girls and guys who come in talking about their training and their diet to make it to whatever class division they need to weigh in at, to be able to participate. Some want to see a dietitian because they need to have certain calories and a certain protein to build muscle and make themselves very lean. And they're working out a lot. We don't tend to think of it or label it as an eating disorder but if you want to get down to the nuts and bolts of it, it's very restrictive.

Within the past couple of months, I have seen two patients with eating disorders. One girl had depression, anxiety and physical issues. She experienced a lot of trauma at home when younger. I had been seeing her for a number of months. Finally, one day, at the end of a 45-minute appointment that was only scheduled for 15 minutes, she blurted

out that she thought she had an eating disorder. I guess she probably didn't have the courage to bring it up earlier. When I think back, I would say that pretty much 100% of the time, with one exception that I will tell you about, it does not come out right away. It's only after multiple visits that they disclose.

For her, she started vomiting after eating because it would relieve her epigastric pain. She also had a history of self-harm. I think that the vomiting became a habit and another way to abuse herself or not take care of herself, or to relieve physical and mental pain. Although patients can self-refer, I made a referral for counseling because I wanted it known that I was really concerned and hoped that they would see her on a more urgent basis. The ball is still in her court as to whether she chooses to follow up. She had been referred on to gastroenterology and psychiatry. But she is also a patient that will go to her family doctor, she'll go to Emerg, and she'll go to a walk-in clinic. The last time that I saw her, she'd been to see 5 other people in between her last appointment and the most recent one. Then it is very, very difficult to try to reel everything in, to get that continuity of care, and to get a full sense of what's happening with her. With her it's been very muddled and convoluted. I take a collaborative approach with more complex patients and eating disorders absolutely would fall into that realm. I've talked to her about how important it is to follow up consistently with one person as much as possible so we can work together to get her to a better place in all aspects of her life.

Now, another girl, I've only seen once and it's a very, very strange situation. After she left, the triage nurse and I said there was something not right with her story. We both had questions about what was going on. She was a very, very, very tiny girl. I didn't question that because she looked proportional. She was very well put together. In her

history, she disclosed that she had been treated for eating disorders in the past but that she never had an eating disorder. She had seen a psychiatrist and had been to counseling but she said that her parents made her because they always felt that she didn't eat enough. She said that her family are big eaters who celebrated with food and she just never had a big appetite, so they always felt that there was something wrong with her. She said that after a while she started to believe that it was true and that's how she ended up with these care providers. She was having issues with epigastric pain. We talked about taking a particular medication that had been prescribed to her in the past but she had never taken it because it bothered her stomach. When I said that she has to take it with food, right away she asked how much food does she have to take it with. I questioned if it was a problem for her to take medication with food because we just talked a lot about disordered eating. Not wanting to take medications because she has to take it with food was a screaming red flag to me. But she denied having an issue.

Working with individuals with eating disorders is tough because of a lack of follow up on the patient's behalf and not coming in consistently. The other struggle is that they are more mobile at that age. There are two key things, the fragmentation of care that makes things difficult, and the patient buy-in and their ability or willingness to participate in order to get to a better place. The continuity on both sides is huge when you are working with someone with a condition as complex as an eating disorder. It would be a lot to take on if there were several patients who needed that level of intensity. I have the capacity to do lots of follow up and to book double appointments. Although nurse practitioners can order diagnostic tests and refer to specialists, we don't have hospital privileges. I haven't had the experience of referring out of province for eating disorder

treatment but I know colleagues who have and out of province billing is another issue. I know from seeing colleagues who have worked with very sick patients with eating disorders that it is very demanding and stressful. The parents of these patients were so overwhelmed and so appreciative of the care. It was heartbreaking on the one hand and heartwarming on the other. These physicians were calling all over trying to find where these patients could go. So physically, people were saying they can't take her or don't want her while mentally, they were saying, no you need to do this. Somebody has to do something. We can't lose people between the cracks. And for these two patients, these physicians did not stop until they found somewhere for them to go.

I wish that there were some formal, basic information and training to better equip us as front line primary health care providers. We need training about the best approach to take and the best things to say. We also need a go-to list of resources that would take some time away from having to do the research ourselves about what is out there and where we can refer. It's the concrete, useful information that I could use as a health care provider to work best with these patients; recognizing that I am one piece of the puzzle. But, I'm the front line person who is going to see them, and maybe pick up on it and be that lynchpin for all of the other care providers that need to be involved in their care.

Participant 05

In medical school, I was exposed very little to eating disorders. I actually could not tell you that I remember specifically any patient or class that addressed this issue.

Medical school is not about learning everything there is to know. Like any profession, it's about learning how to problem solve, how to listen, and how to communicate. If the patient is sick, when is this situation urgent? What does the patient want, how are you going to deal with what the patient wants and what does the patient need? You are problem solving and then when you reach a wall when you've sort done everything that you can, and then you need some help.

I think the biggest line I would draw is if the patient is physically sick. I mean, is there a sense of urgency about this because this this person is going to develop a serious medical illness? That is where the stress comes in. I would go to medical meetings and made sure to go to those parts of meetings that are relevant to the areas that I felt I needed to know more; to self-teach.

I think we are taught some of the skills to be able to deal with eating disorders. But in terms of how to treat, no, I don't think we are taught enough. I've been in practice for twenty years. Initially, my experience with patients would have been sort of stepping in and stepping out and not really having to care for anybody with an eating disorder over a prolonged period of time. I am sure that at that time period, I missed a lot because the question didn't come up and I didn't ask. It's not always something the patient wants to talk about.

Knowing what I know now, I have seen an extraordinary number of individuals with eating disorders. Most of them do very well. The one's that will walk in and say, 'yeah, you know I have an eating disorder', and are more open about it, can actually be functioning better. They are open to treatment and they want to talk about it. They are

coming asking for help. The sicker patients are the ones that are better at keeping it under wraps for a longer period of time. That's the difference.

I had quite an in depth experience with one particular patient. The young woman very quickly got very sick and had to stop every activity. She was not socializing or going anywhere, couldn't work, and had to leave university. I worked with a dietitian with a lot of experience, which was really helpful for me. She was the one who had raised more red flags that this was going to go in a not so good direction because initially, there wouldn't have been a lot physically. But she, having seen more sick people and more red flags early on, knew there was going to be a concern. So I had her help a lot and also psychology and we were all involved. It was very draining. It really was exhausting and I needed the emotional support.

At different points, we were able to have meetings all together. I had such confidence in the dietitian because she had dealt with so much of that. I really did have somebody with a lot of experience. Patients need somebody to focus on how to safely deal with the nutritional aspects. The dietitian would give hints and then I would read her assessments and would start to say, 'ok, now here's the questions that she is asking that's bringing the issues out more so'.

I was able to piece it off a little bit because I am really not a counselor, although I do lots of counseling as a family physician. And then, there is still a lot of stuff left over for me to do after all that. So it was really nice to hand off parts to people who were well trained to do that.

I think it would be helpful for the family and the patient from the very beginning to have someone sit with them and give a better idea of the potential outcomes, a real

honest assessment of the potential outcomes. Every family's worse fear is the most severe outcome, which is death. As soon as it was obvious that this patient wasn't going to be one of the ones who did well, but was getting physically sicker and sicker, it would have been nice very early on to have somebody who saw lots of people like that.

So this particular family got to a point where they sat in front of a specialist and were told very clearly, that at that point there was nothing else to do unless she got worse. The family could accept that their option was to keep doing what they were doing and do something differently if that point got reached. But before that, they're sitting home, and I am too, sitting here feeling like, 'is there is something that I am supposed to be doing differently'. The stressful thing was not feeling that I couldn't do anything because there are things in medicine that I can't do anything about and I just get to that point. It's the feeling that there might be something better but for financial, or location, or other reasons, I can't access what is needed. That's the frustration. It's the unknown. I think it's the unknown and the responsibility. It's not about me in those scenarios but at the end of the day, I know that I offered somebody the best possible chance of getting better.

I was mad about it, at the time. I can't think of another diagnosis where I don't have someone to call. If I have something surgical, I have a surgeon. If I have a lung problem, I've got—. In this situation, this was a psychiatric diagnosis that psychiatrists don't see. That is what is different from other disorders. Because the answer I got was 'all these things don't work'. Whatever led to that decision that 'we don't do this because it doesn't work well' needs to be handed on. It took finding somebody to just say, 'I'll do it. I'm happy to do it'.

In the end, I managed to get a specialist on the phone from another province that just answered 10 or 15 questions for me. He was able to answer the questions I had that I couldn't answer for the family and then I could go back to the family. I think a lot of times, it's not that there is anything different out there. It's just I need to know that before I can be comfortable.

I really felt strongly, and was trying to figure out who I let know that this is not ok. I had another health professional tell me that I was too emotionally attached to this patient. And I wasn't. I think I am a caring person. I'm watching the whole family and I'm thinking, it's really unfair because if it were some doctor's daughter in this community, the patient might have better financial resources to just go somewhere else—but no one I know would watch their daughter go through that and accept the care we had. Nobody would. *And the response was that I was caring too much!*

How do we have a community where we've just accepted that we don't deal with it? Why are eating disorders different than any other medical issues that are in front of us? Why is it ok to not have a plan? Why is it ok that we have that in every other area, but we accept that we're just going to let these people with eating disorders float around and some are going to spend money in private clinics so they won't be our responsibility?

It was extremely time-consuming trying to advocate for that patient and her family. It was really difficult because it was hard to find help. It was hard to find resources. As that patient's illness progressed, the resources were really lacking. It was hard to have any justification for the lack of resources for the patient herself but also for the patient's family, whom I was really involved with. You are talking about a young person who is an adult, but just seventeen. You know, like anybody's daughter. The

medical community does not seem to be able to come together and advocate for patients. You are either insulting a colleague or questioning the politics of it all. There exists programs but I had to go outside of our province to make that happen. When changes are made, it seems it is always the patients that make it happen. It's kind of sad but I think that is the reality of most things. It could have been much nicer on the family, I think, if the resources were better.

Participant 06

I've always had an interest in eating disorders. I started my career in nutrition. But, I thought if I become a dietitian, I don't know that I would be able to get to the root of the problem. As a student, during eating disorder week, I happened to do a presentation that led to becoming a psychology resident with a focus on eating disorders. I sat on an eating disorder advisory committee that was keen on spreading awareness and we started to organize conferences once a year. We had a New Brunswick eating disorder group for peer supervision. We learned what other people were doing by connecting every month to talk about difficult cases. It kind of fell apart eventually. My initial experience was mostly through my residency supervision and just my own learning through workshops and reading. Early on, I was a facilitator for eating disorder support groups for teenagers 16 and up, and young adults.

I work with patients with eating disorders in my private practice. When clients were hospitalized, I think it went pretty smoothly. Every week, they met with the

pediatrician or the psychiatrist depending on their age, and their parents, and whoever else. I would make sure to be involved so that once they were discharged, I would be able to continue the care. In my former practice, I would consult with the psychiatrist or the pediatrician but that was always a little bit harder; it was usually my supervisor, a dietitian and myself. Our plan was to get a physician on board but they are so busy in this province. In my current practice, I will ask family doctors to do blood pressure, weight, and sometimes blood work. With bulimia that is moving toward restrictive eating, it's not always on a doctor's radar, so involving them in the care is useful.

Sometimes hospitalization isn't that helpful. It's helpful in the sense that it brings clients back to being medically stable but I personally prefer to intervene before they get to that point. If pediatricians or family doctors can make a referral as soon as there are some warning signs, I find that works better. Then, we can do a home hospitalization. Otherwise, clients are in hospital with limits and supervision and then when they're back in their environment, parents don't know what to do. Clients are very vulnerable when they go back home. It's all about changing their environment and they need a lot of support. I treat it very much like an addiction. I tell them, it sucks that this is your addiction because you have to learn to manage it, whereas we would never tell an alcoholic, 'well yeah, keep the bar stocked at home but just don't have any' or learn to manage it, in moderation.

You cannot just work with the teen; you have to work with the parents, too. It's taxing on the parents. I recommend one of the parents take time off work after hospital discharge. I would write letters or get the family doctors to write letters to the employer. When parents took a month off, it was more helpful and a lot less stressful on the family.

We would do a kind of hospitalization after the discharge, too; doing the meal support and supervising activities, depending on how sick the child is. Because this happens in the home, we get to the nitty-gritty. Families look perfect on the outside but as soon as you start doing that process, everything comes out and the whole system is shaken up and under tremendous stress.

Parents are sometimes over protective. It's not necessarily that the parents are doing something wrong. It could be a poorness of fit. The personality and the sensitivity of the child may be fueling the eating disorder. These teenagers are often, but not always, people pleasers and the protector of the family. They are very quiet and don't speak up, and during these times they get quite angry. The eating disorder becomes that piece that they can control. When we start the re-feeding process often times all of the weight goes to the stomach, so I talk about the healing bump to prepare clients. I tell them that the weight will re-distribute once their body knows it is not starved anymore. It's the little things so they are not taken by surprise. Parents become in distress because it's the child they never had to worry about. Some parents tend to minimize and I have had to purposely amplify the crisis. Often families will think 'well just start eating or stop purging'. Families need to understand the severity and why it is not that easy to get better. This also helps with buy-in from the client. It often gets way worse before it gets better, so I find it gives me a lot of stuff to work with.

Eating disorders are very specialized. If there is any area that therapists could do damage, it's eating disorders. Professionals have to be careful about comments. Often clients have major issues with boundaries. I've had to undo some of the things that physicians and pediatricians have recommended to the parents and the teenager and that's

really difficult. All of a sudden you lose your client for a little bit. They are pissed off because you are going against the doctor. Maybe they are out of woods in terms of being medically stable but it's a slippery slope. It's very easy to go back down and you have to continue that work much longer than just being medically stable. Health professionals need to have some knowledge about what not to say, and what not to suggest, and when to recognize that it is out of their scope. I have seen a lot of clients with eating disorders and still often I feel like I'm treading water.

At times, I will do motivational stuff if clients are feeling like this is not an issue. Clients with a kind of sub-syndrome, with no diagnosis but some disordered eating, can be difficult. Sometimes there are secondary gains that come with being sick. Clients can be on the fence about wanting to get better because they don't have to focus on what they want to do with their life or to engage in relationships. Sometimes, I don't really feel like they are progressing. They seem to identify with being an eating disorder client and are stuck in a pattern. Those are hard, particularly when there is personality stuff mixed in. It's important to recognize that even with experience, professionals can get comfortable and just go along, not presenting anything new. It's important to shake things up for clients that are stagnant so that they can move forward.

It's a serious, pervasive condition. If left untreated, they can die or continue to have issues into adulthood. There are no resources. I've sent people to the hospital in the past and it doesn't work. Unless they're medically unstable, they are not going to get a bed. So that's not an option. They can't get the support that they need at the mental health center because there is not necessarily anybody who is specialized and when you refer somebody, you can't even choose who they're going to see. Some clients can wait six

months for service at mental health. With an eating disorder like anorexia, where they are just on the cusp of almost getting to a healthier weight range, this is too long to wait. And there is no financial support. If they can only come to see me once every 4 to 6 weeks because their parents can't afford more than that, it's not that helpful and they don't get much better. The one's that see me weekly, progress much more and have a much better chance of getting better.

It's very frustrating to provide care in this province! We know from research that the shorter period of time that they've been sick, the quicker the rehabilitation will be, and the better the prognosis. It's terrible that families and parents have to pay all this money. If they can't access it through a provincial program then it should be covered through Medicare, if they have to go privately. I just find it's too bad. Even if it were just covered for 6 months to at least get them on track, it would be helpful. Hopefully, someday maybe, there will be coverage for these kids.

Participant 07

In hospital, we get some people admitted with eating disorders. Even with adults, a team is consulted. Dietitians will get a consult, 'poor eating', 'not eating', or sometimes it will say 'eating disorder'. I do get some patients that are around 19 to 21 on the floors. I will talk to patients to find out where they're at and what we can do to help. If they have no interest, I can usually get that idea at the very beginning. There is not a whole lot that I can do if patients don't want to have any intervention. If they don't want to see a dietitian or talk to a counselor then it's just trying to get them medically stable to be discharged.

There are weekly rounds on the units. With patients with eating disorders, usually family doctors, dietitians, psychology and occupational therapy are involved in the beginning. Psychiatry is very difficult to involve. We may think that a patient needs to be seen but psychiatrists will just say no. It seems to be their go-to response. Dietitians meet every day to discuss cases. If we have somebody that we're finding is difficult to deal with or don't know what to do, we consult each other. Sometimes we will wait until psychology tries some intervention first. The other health professionals will peter out and maybe psychology is the only one continuing to see them. I peter myself out when patients say they don't want to see me. Sometimes patients have to be feeling better. Like everybody else, if they are feeling sick, they don't want to eat. Maybe once they start to feel better, they might be more apt to follow nutritional intervention.

Dietitians provide education to patients about how the nutrients function to keep their body alive. Some people don't realize that we need calories just to keep our heart pumping and kidney filtering. People don't realize what calories are for and think they are either going to exercise or body fat. Calories tend to be what people are most afraid of. They may know a lot about the calories in the foods or even the nutrients, it's just putting it together with the medical aspect. So, dietitians will break it down into nutrients that their body needs to keep them healthy, functioning, and feeling well.

I recently had a 30-year old patient that I don't know if she has an eating disorder or not. She won't touch anything off the trays. She might have a few pretzels that are brought in by her mom. She can eat. She just won't. She has been in and out so often and has been admitted for months now. She's on a tube feed. At first, they thought it was an eating disorder but it may be other psychological issues. I guess with eating disorders,

there could be some of that, too. She complains a lot of pain in her stomach. Whether it's actual GI pain or pain somewhere else, I'm not sure. So the tube feed will go, everything is fine, and then it's not and she wants it stopped. They eventually talked her in to getting a permanent tube put in. That would have been through some of her good times that she would have agreed to that.

It's very difficult to talk to clients about making a change. They know about good nutrition and what they should be eating. It's about getting them to make small steps or eat a smaller amount, three times a day or to find that one food that scares them and incorporate it into their day. A lot of clients are focused on the weight on the scale. I have clients who want to get to a size 2 or one lady that wanted to be 100 lbs. because it's a nice round number. I see some people who may be on the heavier side but they look good because they know how to dress themselves. I had one teen that wanted to know her weight. I didn't want to and explained why. But, she wanted to know and then started crying when she got on the scales and that was the end of the session. She was devastated. A lot of dietitians put clients on backwards so that they can keep track but the client can't see the numbers. There has got to be a better way to judge when our bodies are at a good place for us.

I had two patients with eating disorders in private practice, both females. One came at the request of her counselor and another dietitian referred the other. One client came back from an eating disorder clinic so she had a lot of counseling. She saw a dietitian at the clinic and had developed some skills so it seemed like it was pretty good. When her weight started to go down, she was to take Ensure on top of whatever she was eating. I remember that she was still measuring everything to make sure that she was

getting the amounts that she was supposed to be eating. After a month or so, she said that she is not really measuring right to the top. She still had those habits of needing to reduce intake. She would tell me about going to the store and how she hated looking at herself in the mirror. Even though she had gone to counseling, she still had poor body image. She wasn't supposed to exercise but would choose to go the longer way, up the hill, to exercise more. It was still engrained in her mind that she had to lose weight somehow. That's not part of my role to talk to her about her body image. My role is more about healthy nutrition. Sometimes it's like talking to a brick wall. I am saying the same things every week; trying to find a different way of saying it or another way to incorporate good nutrition. It's very frustrating.

I didn't have a lot of specific eating disorder training. If there was any when I was in school, it was very small. I remember some of the major diseases but nothing specific to eating disorders. Through internship, some dietitians would go to a facility for eating disorders but I hadn't done that. There have been some webinars that I've done. At a conference or two and there was a session on eating disorders. At one conference in the States, they talked about re-feeding syndrome, and putting patients on TPN, or enteral feed. Although it was a conference on sports nutrition, it would be along the same lines. Whether you are an athlete or have an eating disorder, you do a lot of activity so a lot of that information is transferrable. One colleague would go to pediatric conferences and bring back information to share. As far as training, that would have been all that I have had. Even over the course of a couple of years, practices change depending on the research. Because I don't do a lot of this work in the hospital, it is not part of the training that I would seek out.

A big problem for the younger kids lies in media messages and wanting to emulate stars and models that are stick thin; standards that most people can't attain. I think a lot of women have, not eating disorders, but disordered eating to some extent. There is a lot of news around gluten, starch, and portions. People think this information is the truth and then dietitians have to justify why it's not. Even I question myself and I know better. How much more is it going to affect someone who doesn't know? Do we eat to enjoy life, as long as we're eating mostly plants and having some protein and variety? For people that want to eat healthy, or have diabetes or other conditions, we teach portion sizes and what foods to eat but are we structuring it too much? We don't want to be a slave to portion size.

People get a lot of advice from those who are not trained professionals. I once had a family who was concerned that their teen may have an eating disorder. In the end they cancelled with me because they discovered the trainer at their gym talked to people about diet. And, I am thinking what might he say that would trigger her further into a spiral of eating disorders because they don't have the training. It's all about following menus, portions, and not eating grains; whatever their thoughts are on healthy eating. We have to watch what we are saying and to know what to look for. We don't know people's backgrounds and what we say can play a big role in developing disordered eating. There is all this pseudo-science about nutrition. Not all research is good research. Some people doing nutrition might just be cherry-picking different research, where dietitians want to make sure that information is comprehensive, and that it is not going to harm anybody. We are regulated and in that sense, we are protecting the public, too.

Sometimes people have physical characteristics of an eating disorder. There was a medical resident at my gym and she'd be sweating it up on the stair climber. I could see the bones all down her back and her shoulder blades and she had a really drawn in look and I just knew she had an eating disorder. I don't think that I would want a doctor that had an eating disorder. I would wonder about their mental capacity and would question if they would be able to really think about what I needed.

Patients who are obese probably ring a bell for me more than the skinny ones with the bone protrusion. Although it doesn't look the same, even people who are obese develop eating disorders. I have had some really morbidly obese clients and their idea about losing weight is not eating or only eating one meal a day. They would never get to the point where they would be emaciated but it can still affect their health. They can still be malnourished and obese. After years of eating poorly, unless they take drastic measures like exercise and eating right, they will not lose weight. They will have intermittent spurts where they will stop eating or not eat much. Their eating disorder or disordered eating is more hidden and comes out from conversation. I remember one physician from a weight management program talking about this one lady. He had written out what she ate and it was the exact same thing every day. She was afraid to deviate from her normal patterns because maybe she'll gain weight. She is not getting the variety of nutrients that dietitians tend to promote. So, is that an eating disorder? We get a few hospital consults for obese individuals to help them to lose weight but weight loss of any kind is last on our priority list. Patients are here to get medically stable to be discharged and sometimes they are too sick to hear us anyway. We will refer them to outpatient services.

In hospital, we try to find out where best to send people in the community. If patients don't have private coverage, they have to pay out of pocket for private dietitians. Dietitians at Sobeys and Superstore can help patients learn to read food labels and are free. The New Brunswick Association of Dietitians put a list together but I would still have to be calling around to know who specializes in eating disorders. There should be an easier way. There was something on the news not too long ago where the person with an eating disorder couldn't find someone to help her. She fell through the cracks. Patients with eating disorders need a team. And unless people are going to bigger centers where they have big clinics, getting a team together might be more difficult. A lot of dietitians won't see someone for an eating disorder unless they know that there is some type of a counselor involved. I can tell you what to eat but if you don't have any type of support helping you to eat and helping to mentally wrap your brain around it, then it probably is going to be a waste of money.

Participant 08

My experience working with individuals with eating disorders is relatively new. Traditionally, I had not had any referrals as an inpatient-outpatient occupational therapist in a rural setting. I would never have anticipated working with this population in a rural community. I fell under that myth that this kind of thing happens in a larger center, it doesn't happen here. Therefore, anyone with an eating disorder needs to go to the larger center where the expertise is located.

However, several years ago, within one week of each other, I received two patient transfers; one from an in-patient hospital setting and one from a residential treatment center. At that point, I wanted to make sure that I was providing the best practice. I had a good understanding of the role of an occupational therapist in an inpatient setting but I was a little confused as to what I would be able to provide in an outpatient setting.

In university, there may have been one session on eating disorders in the mental health portion but nothing that I could tap into from memory. In terms of my understanding, initially, I would fall into the same category as most of the public, thinking that eating disorders were simply a cry for attention and really minimizing the impact that it has on families. Learning about the condition has really changed my perception; including society's role in creating this ideal body image that people strive for and looking differently at the multi-million-dollar diet industry.

As I did my research, I got my feet under me. I partnered with a dietitian, who also recognized that services were lacking. Together, on our own time, we created our own program. Since then, it has grown exponentially. Now we see quite a few people, primarily on an outpatient basis. The majority of patients are teenagers but we've seen people from the age of eight, all the way up to the age of 53. Working in a rural setting, that's typical anyway. We see a little bit of everything so it wasn't hard to adjust.

Initially, it was a matter of getting research articles, resource books, and a DVD series. There was no time to research resources during work hours. I don't just work with people with eating disorders. I cover both outpatient and inpatients and work in three different facilities, so I had to look for resources on my own time. I found one book specific to occupational therapy but it was primarily from an inpatient perspective. I have

not had the opportunity to link with anybody providing occupational therapy services on an outpatient basis. When I asked an inpatient OT from another region for resources, the emailed reply was a link to two websites. That gave me a flavor that everybody else must be struggling with their knowledge, too. I check eating disorder websites for training but a lot tends to be on the west coast so the probability of accessing that is slim to nil. If we could arrange it, we would be approved to go to an out of province hospital to see what their day program is like.

In very simplistic terms, how we approach the work, is the dietitian looks at the energy input and I look at the energy output. My focus is on the patient having more of a balance in their activities, which tends to be difficult. Regardless of what eating disorder it is; either you have someone with too much activity or someone who has not quite enough. We also look at body image and perceptions of self. It's all about looking at activity and balance. Some patients are lacking in certain activity areas. So, if they're struggling with social engagement, then we look at social wellness and how we can help them engage in their community, school, and with family. Work wise, if an individual is struggling with employment options, we can steer them in the direction of where to go. I'm not always providing the direct intervention.

When we first start working with parents, there is almost a sense that they can take a breath and can stop worrying now that their child is linked. We get a sense that parents like to wash their hands of it once they get some help. And it's not that we tell them that you need to continue to worry. But we do tell them, this is a long road to recovery and there is still going to be bumps along the way. The struggles that families face when trying to help their children are not just emotional stress but a financial burden,

as well. When their child is hospitalized, they're hospitalized two hours away, and the expectation is that parents take an active role in their child's treatment. Although I understand the need for parental involvement, there is a financial cost to leave work, and put gas in their vehicle, and to leave other children at home and make arrangements for their care. I can see how that can be very, extremely overwhelming.

We have a rural 21-bed facility so it does not typically accept individuals with eating disorders as inpatients. There was only one instance where we saw someone on an inpatient basis. This individual, from a rural community, was in and out of hospital five times. The in-patient team and her local team recognized that this was not working. So, on her last admission, they caught wind of the program that we had created and wanted to trial her through it. In a team meeting, we decided to do a step-down approach with her. She was transferred to the local hospital and my colleague and I provided training to the staff. We did the meal support with her and arranged meal support by family. She was there for a total of 55 days. From the in-patient setting, she was discharged and we followed her as an outpatient. She has since been successfully discharged from our program.

We have linked with a pediatrician who has been a real champion for outpatient eating disorders treatment. For patients who come on our caseload, we consult to figure out at what point to send a referral. When we get a referral from a physician who is new to our program, we'll take time to meet one on one to explain our program and to make sure everyone is on the same page. We have access to respiratory therapy to do vitals and nursing will also assist after hours. There is not one identified nurse and consistency and

training can be a bit of a problem. People always mean well but even one small, misinformed comment can cause harm.

Treating eating disorders is a specialty. Unless professionals have a passion, and are willing to beef up their knowledge on their own time, it can be a bit of a struggle. As it is a mental health condition, we recognize the need to find mental health resources for patients. We have tried accessing the social worker at our local facility but that didn't really pan out. There are private psychologists but you've got to have private insurance coverage. We can access community mental health. We've come across instances where patients were discharged when they shouldn't have as there continued to be issues playing into the eating disorder behaviors. So, it's a very tricky area accessing mental health. In rural settings, it is extremely difficult pulling together resources.

Depending on the acuity of the referral, we can see patients anywhere from weekly, to bi-weekly, to monthly. As they progress, we try to wean them, going every two months, then every three months, and then just for re-checks. We have a two-visit assessment process. We talk to patients about the fact that there may be the occasion where they see us in the community but that they will not be "ousted".

There is a lot of stigma attached to eating disorders so people are very resistant to having workers come into the school and pull them out of classes. Patients don't want to miss a whole lot of school so most of our visits happen after work hours. We have started to talk about our hours, as we are probably a little too flexible. We have to be careful that we are not doing more work than the patient or that our own personal lives aren't being compromised.

My colleague and I have been around for a while, which tends to happen in a rural setting. One of the problems in the urban centers is that there is so much therapist turnover. They don't have an eating disorder program or clinic the way that we do in a rural setting. We see it as a bit of a coup for us because we've created a little bit of a niche. Initially, it started with those two girls that were transferred and it has slowly grown, from the small rural community where we are, to spreading our geographical base to include people from the city. It's so very exciting! And, I love the fact that we worked hard at getting the message out. You need to travel where the expertise is. So, just like people where we live need to travel south for cancer treatment, well, anybody with an eating disorder needs to travel north.

We had no intentions of re-inventing the wheel. When we went looking for resources, we found little pockets of individuals who treat eating disorders but there is no coordinated clinic or program. And that's what is required. Look anywhere in the literature and it talks about an interdisciplinary approach. I don't think every area needs to have an eating disorder team but whatever ends up being developed has to be a coordinated effort.

Appendix F: TCPS2 Certificate

PANEL ON RESEARCH ETHICS <small><i>Navigating the ethics of human research</i></small>	TCPS 2: CORE	
<h3><i>Certificate of Completion</i></h3>		
<p><i>This document certifies that</i></p>		
<p>Tanya Wilson</p>		
<p><i>has completed the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course on Research Ethics (TCPS 2: CORE)</i></p>		
Date of Issue:	1 June, 2014	

Appendix G: Abstract

21st Annual Research Day: "Moving Research to Policy and Beyond"



Tanya Wilson, BSW, RSW, Graduate student – Applied Health Services Research, UNB - Fredericton and **Kathryn Weaver**, BN, MN, PhD, Associate Professor, UNB – Fredericton

Contact: twilson@unb.ca

Title: NB Allied Health Professionals Experiences in Working with Individuals with Eating Disorders

Health professionals struggle with caring for individuals with eating disorders, especially in New Brunswick where there is no recognized eating disorder treatment center. This research study currently under way enlists allied health professionals to share their experiences in providing treatment and intervention to individuals living with eating disorders. Working within a larger Atlantic Provinces study, New Brunswick health professionals were invited to reflect on their experiences, perceptions, and training related to caring for individuals with eating disorders. Use of narrative methodology is a helpful approach to gathering the stories of social workers, dietitians, nurses, physicians, and others who have been entrusted to care for clients affected by eating disorders. These stories are being collected and analyzed to identify common threads and themes among NB health care providers. Although findings are pending completion of the research project, this presentation will highlight a few of the core stories that have emerged from the preliminary analysis. These emergent findings provide insight into the needs of healthcare providers and may ultimately inform existing and developing treatment and prevention initiatives.

Curriculum Vitae

Candidate's full name: Tanya Lynn Wilson

Universities attended: Saint Thomas University, 1992 Bachelor of Social Work degree

Conference Presentations: 21st Annual Research Day: Moving Research to Policy and Beyond, UNB Faculty of Nursing, Fredericton, NB