2020

Understanding the Experiences of Young Adults Receiving Community-Based Eating Disorder Care

Hali Sitarz
Walden University

Walden University

College of Health Sciences

This is to certify that the doctoral dissertation by

Hali Sitarz

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Review Committee
Dr. Kathleen Brewer, Committee Chairperson, Nursing Faculty
Dr. Donna Bailey, Committee Member, Nursing Faculty
Dr. Maria Ojeda, University Reviewer, Nursing Faculty

Chief Academic Officer and Provost
Sue Subocz, Ph.D.

Walden University
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Abstract

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MN, Athabasca University, 2011

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Nursing

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Abstract

In Ontario, Canada, eating disorder care is predominately delivered through nurse practitioner-led community outreach programs; however, there is a paucity of evidence informing the role of nurses in terms of outpatient treatment, community-based care, and young adult patient experiences. With high rates of morbidity and mortality, it is imperative to establish an evidence-informed approach to eating disorder treatment and ensure that care is patient-centered. This interpretive phenomenological study explored the experiences of young adults receiving community-based treatment in Ontario. Reigel, Stromberg & Jaarsma's Middle Range Theory of Self-Care in Chronic Illness was used as an orientating framework. Seven young adults, aged 18-22, who were undergoing community-based treatment for anorexia nervosa or bulimia nervosa across the province were engaged in two asynchronous online focus groups to discuss their experiences. Themes of living with unmet needs, living with supports, and learning to live again emerged from data analysis using Interpretive Phenomenological Analysis and constant comparison methods. Participants revealed highly variable community-based treatment experiences, inconsistent delivery and their need to delineate a definition of community-based treatment in future research. Collectively, young adult participants aspired to individualized, holistic, accessible, structured and team-cohesive community-based care in the future. Findings have the potential for positive social change by raising awareness of the unique needs of young adults with eating disorders to inform quality care delivery. Results may also prompt further research inquiry and inform clinicians, organizations and policy makers in their efforts to ensure quality standards in Ontario eating disorder care.

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Dedication

I dedicate this dissertation to those who battle eating disorders and to the health care professionals who support them.

Acknowledgments

I’d like to express my gratitude to the many people who have supported me through this process. I am so thankful to my husband, Scott, for encouraging me to pursue this journey, quietly enduring it alongside of me and for holding things together when my attention was directed away from our family. To my parents, I thank you for always encouraging me to be tenacious and for your practical supports along the way of each academic pursuit- I promise that this is the last one. Thank you to my friends who provided much needed distraction, humor, and cheer-leading, especially Lizette Keenan who was always there to celebrate successes and to re-focus me in times of doubt. And finally, to my daughters, Quinn and Blair- I hope my efforts in this endeavor teach you that pursuing and achieving goals *is* the reward and that this example drives you toward your own ambitions.

I would also like to thank my teachers and mentors at Walden University. Through the guidance and expertise of Dr. Kathleen Brewer, Dr. Donna Bailey, Dr. Maria Ojeda and Dr. Leslie Hussey, I have grown so much as a nursing scholar.

Finally, I wish to share my appreciation to the participants who invited me into the intimate details of their lives so that we could take steps together to make life better for those who are afflicted with eating disorders..

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Chapter 1: Introduction to the Study

Introduction

Eating disorders are known to have the highest mortality rate of all mental illnesses in young adults (Fichter & Quadflieg, 2016). They are also associated with significant morbidity in the forms of both physical and psychological complications (Mehler & Andersen, 2010). Further, individuals with eating disorders report poor quality of life (DeJong et al., 2013) and psychological well-being (Tomba, Offidani, Tectua, Schumann, & Ballardini, 2014), as well as impaired cognitive and emotional functioning (Harrison, Tchanturia, Naumann, & Treasure, 2012). Despite these significant complications, many individuals with eating disorders do not receive adequate treatment due to the barriers they face (Hart, Granillo, Jorm, & Paxton, 2011; Thompson & Park, 2016).

Several factors have been identified as influencing eating disorder treatment. These include individual personality traits and health beliefs, stigma and shame, geographical and financial barriers, and beliefs of healthcare professionals and patients' past experiences with them (Innes, Clough, & Casey, 2017). Only 10% of afflicted individuals overcome these barriers to receive treatment, and most do so in outpatient, community-based settings (Eating Disorders Coalition, 2014; Thompson & Park, 2016). Individuals with eating disorders who have access to health care services often go undiagnosed or they fail to engage with treatment once referred (Hart, Granillo, Jorm, & Paxton, 2011). The practice of nurses in community-based eating disorder care is not evidence-based as most research has focused on treatment in in-patient, hospital settings and has been conducted by physicians and psychologists through discipline-specific lenses. There remains a paucity of evidence to support eating disorder treatment, particularly in the community-based setting and relating to nursing practice.

With the complex, chronic, and enduring nature of eating disorders and poor outcomes if left untreated, paired with the lacking evidence-based nursing practice, further inquiry into community-based eating disorder care is an important priority. Hannon, Eunson, and Munro (2017) advocate for qualitative research to be conducted to fill this gap in the evidence in order to give voice to those in receipt of community-based eating disorder care. Further, an improved understanding of the patient experience in community-based eating disorder care has the potential to inform practice changes and improvements that can address the current barriers to treatment and improve access to many more individuals suffering from eating disorders (Sheridan & McArdle, 2016). This understanding is an important facet of the evolving interdisciplinary care approaches for treatment teams, and thus, this research can benefit all members of the treatment team, not just nurses.

This research has the potential to inform both patient priorities and nursing's role within community-based eating disorder care. This may substantiate additional inquiry and support policy change that will result in patient-centered practice change and more prescribed nursing care. With an expanded understanding of the role that nurses play in community-based eating disorder care, opportunities for increased and strengthened multidisciplinary care and funding may abound.

In this chapter, I will review the topic background, present the current problem, research questions and significance, define central concepts, and discuss the orientating framework, nature, scope, limitations, and delimitations of this study.

Background

While the body of evidence involving eating disorders continues to grow, there remains a large research gap in the contexts of nursing care, community-based care, care in Canada, and the care of men with eating disorders. These gaps have remained constant for many years, prompting several researchers to individually and collectively call for the need to develop further eating disorder contexts (Newell, 2014; Newton, Bosanac, Mancuso, & Castle, 2013; Ryan, Malson, Clarke, Anderson, & Kohn, 2006; Snell, Crowe, & Jordan, 2010). In 2001 Wiseman, Sunday, Klapper, Harris and Halmi (2001) identified a trend whereby eating disorder treatment was shifting from long-term in-patient care to in-patient medical stabilization, which subsequently, increased the need for out-patient care. More recently, Hart, Granillo, Jorm, and Paxton (2011) identified that large numbers of people are seeking eating disorder treatment in the community, yet few are receiving the care that they require. In Ontario, Canada, where eating disorder care is organized, funded, and delivered in the same manner that Wiseman et al. (2001) described nearly two decades ago; nurses are heavily involved in community-based eating disorder treatment, yet there is little evidence to address the Canadian and nursing contexts necessary to validate current practice. Finally, current practice standards and research excludes the specific needs of males from eating disorder care. Cohn, Murray, Walen and Woolbridge (2016) asserted that the predominance of females with eating disorders may be overestimated, and as a result, this has narrowed research and program development to exclude the needs of males afflicted with eating disorders. Further, men face significant stigma and as a result receive less education about eating disorders, are less inclined to seek treatment and are excluded from research that could inform practices that improve care for them (Cohn et al., 2016).

Hannon, Eunson, and Munro (2017) explicitly identified the literature gap that exists for community eating disorder care. Their phenomenological study examined the experience of community-based therapy for individuals with severe anorexia nervosa in the United Kingdom. Their findings elicited understanding of the function of the illness for participants, the willingness and struggle to change that they face, and their experiences of community treatment services. Other researchers have identified positive outcomes of community-based eating disorder treatment. Rosling, Ros, and Swenne (2016) reported strong patient satisfaction with outpatient eating disorder care delivered by physicians in Sweden. Sheridan and McArdle (2016) found similar results in patients receiving outpatient eating disorder care in Ireland. Two Australian studies addressed the potential to improve the continuum of eating disorder care through the development of community-based treatment programs. McCormack, Watson, Harris, Potts and Forbes (2013) found that community-based eating disorder programs improved the perceived capacity of rural health care professionals to manage eating disorders. Newton, Bosanac, Mancuso and Castle (2013) reported treatment efficacy, by means of reduced mental illness and eating disorder symptomology, in patients attending a similar outreach service.

While none of the research about community-based eating disorder care specifically referenced the role that nurses play in this setting, there are several studies that address the nurse's role in eating disorder care generally. Ramjan (2004) and Zugai, Stein-Parbury, and Roche (2013) studied the value of therapeutic relationships between nurses and eating disorder patients and their findings provided support for the role of nurses in in-patient eating disorder care. This support was also evident in Carter, Webb, Findlay, Grant, and Van Blyderveen's (2012) study of the successful integration of specialized eating disorder nurses into pediatric hospital units.

As the evidentiary support for nurses in the treatment of eating disorders slowly emerges, so do the contextual elements of males, community and the Canadian system. However, with the funding and care delivery model in Ontario being currently comprised of nurses providing out-patient treatment to young adults of both genders, there is an immediate need to establish evidenced-based care to facilitate effective treatment that supports patients with eating disorders. To do so, it is necessary to examine these contextual elements simultaneously and starting with the voice of those receiving community-based nursing care in Ontario.

Problem Statement

There is strong evidence of eating disorder research in the disciplines of psychology, sociology, and medicine, yet there is a paucity of evidence addressing nursing care, particularly addressing the community and a Canadian perspective. Most nurse-specific research about eating disorder care involves inpatient settings, yet outpatient services lead to equally efficacious outcomes with less cost, fewer deleterious effects, and greater quality-of-life for patients (Rosling, Ros, & Swenne, 2016; Sheridan & McArdle, 2016). Community-based treatment is a philosophical and operationally different plan of care from inpatient treatment (Bezance & Holliday, 2014) and both health care professionals and patients with eating disorders believe that treatment in this setting is valuable and effective (Findlay, Pinzon, Taddeo, & Katzman, 2010; McCormack, Watson, Harris, Potts, & Forbes, 2013; Newton, Bosanac, Mancuso, & Castle, 2013; Ramjan, 2004). While the role of the nurse in community–based eating disorder care has not been explored in published research, in-patients highly valued their relationships with nurses and these strong relationships improved both adherence to and motivation for treatment (Tierney, 2008; Zugai, Stein-Parbury, & Roche, 2012).

At present, the contextual elements of setting, treatment team, philosophy of care, and geographical location remain poorly understood in eating disorder care. In Ontario, Canada, there is a nurse practitioner-led, community-based model of care for eating disorders and in-patient treatment is reserved for episodic care (Ontario Community Outreach Program for Eating Disorders, 2017). Given that eating disorders have the highest mortality rates of all mental illnesses, and the significant impact they impose on the quality-of-life for those afflicted and their care-givers, it is imperative to establish evidenced-based practices to guide eating disorder care (DeJong et al., 2013; Fichter & Quadflieg, 2016).

Lack of evidence to support current nursing practice in Ontario, Canada, along with consistently high morbidity and mortality rates of eating disorders, warrants the need to establish foundational evidence that addresses both the community and nursing contexts of eating disorder care. This study may bridge these research gaps by directly addressing the needs of patients receiving care in the community setting. As the body of knowledge regarding community-based care of eating disorders develops, this research may impact future policy and funding decisions, underpin the philosophy of eating disorder nursing care, and inform additional research and clinical practice guidelines.

Purpose

The purpose of this interpretive phenomenological study was to gain an understanding of community-based eating disorder care from the perspective of young adult patients across Ontario, Canada. For purposes of this study, community-based eating disorder care was limited to outpatient eating disorder treatment programs for adults aged 18-22, where some or all care was provided by nurses and whereby patients continued to live in their own home. Participants were recruited from several cities to establish an understanding of patient experiences both individually in terms of geography and experience, as well as collectively across the province.

The intention of this study was to explore the experiences of young adults receiving community-based eating disorder care. Eliciting such information may create opportunities to make existing and future treatment practices more patient-centered and evidence-based. Peterson, Becker, Treasure, Shafran and Bryant-Waugh (2016) advocated for research, clinical and patient perspectives to equally formulate the evidence base for eating disorder care but noted that the perspectives of those receiving treatment were underrepresented in the current empirical data guiding practice. As a contribution to research involving clinical aspects of evidence-based community-based eating disorder care, this study was intended to provide data that demonstrates the meaning of the currently funded nursing care in Ontario to the patients in receipt of that care and call attention to the remaining gaps in our understanding of this phenomenon.

At present, community-based eating disorder care provided by nurses is heavily influenced by evidence established in the medical and psychology disciplines. While the nurse’s attention to patients’ physical and psychological care may logically draw from these disciplines, nursing care must reflect the philosophies, and scope of practice unique to nursing. Further, treatment protocols adopted from in-patient care programs cannot exclusively serve as the blueprint for community-based eating disorder care, at least not without strong confirming data. Exploring patients’ experiences involving community-based treatment provided by nurses in Ontario, Canada in this study has the potential to explain community, nursing, and Canadian contexts that are currently limited in the published literature. In their publication detailing the introduction of community-based eating disorder care in Ontario in 2005, McVey et al. identified the need to establish data to determine efficacy, access, and influence of the newly established programs. This study can begin to answer these important questions.

Research Question

The central research question for this study was: What are the lived experiences of young adults receiving eating disorder care in the community?

Theoretical Framework

Phenomenology is both a philosophical orientation and a research approach which posits that truth is derived through subjectivity and people are integral to their environments (Flood, 2010). As a result, meaning can be revealed through sharing history, culture, language, and experience. To describe this idea, Heidegger (1962) used the term being-in-the-world which suggested that the connection between body and mind, and person and environment were inseparable. This concept was derived from the classic phenomenological syntax of 'lived experience'; the focus, value, and intended outcomes of phenomenological inquiry.

Benner (1994) said that ascertaining knowledge to understand a person's lived experience by way of interpretive phenomenological research is guided by exploration of their "…historical change, transformations, gains, losses, temporality, and context" (p. xv). This philosophical orientation aligns with the holistic nature of nursing that provides us an understanding of biopsychosocial data, and it is interpretive phenomenology that situates this data in context and in relation to a participant's lifeworld (Spichiger, Wallhagen & Benner, 2005). Benner (1994) argued that the subjectivity of a Heideggerian phenomenological perspective contributes significantly to the inextricable links of ontology, epistemology and methodology that provides the foundation for both nursing and research.

Phenomenology is a movement in which tenets are rooted in the philosophical underpinnings yet have evolved through the lenses of scholars. This is certainly true of the nature of the interpretive phenomenological tradition, where Heidegger, a student of early phenomenological scholar, Husserl, challenged many of his mentor's assumptions. The focus of Husserl's philosophy and resultant methodology was to glean insight about the subjects' lived experience through 'transcendental subjectivity', or separation of prior knowledge in order to focus on what is being learned as opposed to what is already known (Lopez & Willis, 2004). For this reason, phenomenology conducted using Husserl’s methods is referred to as the descriptive tradition. To remain unbiased to yield trustworthy descriptions of participants’ experiences, Husserl asserted that researchers must neutralize their prior knowledge through a process called bracketing. Bracketing involves separating the researcher’s past experiences, preconceptions, and ideas about a phenomenon to allow the participants’ lived experiences to independently steer understanding of the phenomenon (Lopez & Willis, 2004).

On the contrary, Heidegger (1962) argued that our experiences are inextricably linked to our ‘life worlds’ and as a result we are deeply embedded in environmental context. Lopez and Willis (2004) further explained that this idea of ‘situated freedom’ gives way to an important methodological consideration in interpretive phenomenology. As researchers are also embedded in their own life worlds, it is impossible to be completely subjective as an observer of others’ lived experiences thorough research. To this end, interpretive phenomenology celebrates the expert knowledge of the researcher whereas in descriptive phenomenology, researchers are tasked with bracketing out the context to observe the participant through a purely subjective lens. Bracketing in the interpretive tradition involves the explicit discussion of past experiences expressed in the form of assumptions.

As a nurse practitioner with many years of experience working with adolescents and young adults with eating disorders, I have many views, beliefs, and presuppositions about community-based eating disorder care. Rather than attempt to set these influences aside to conduct descriptive phenomenological research in this field, a task many Heideggerian phenomenologists believe is impossible, I have chosen to use an interpretive tradition in which my *a priori* knowledge can aid in my exploration of the lived experience of this phenomenon. Heidegger (1962) described this as co-constitutionality, whereby meaning is gauged by both the participant and the researcher. Gadamer (1975) described this as a, "fusion of horizons to explain the act of intersubjectivity, understanding, and interpretation" (p. 14).

Focusing exclusively on participants' perspectives, is Heidegger's (1962) concept of 'temporality,' or a notion of time beyond the confines of linearity and instead focuses on "being in time," which draws together past and future to the present. In this study, temporality allowed for the opportunity to learn of participants' experiences and how past experiences and future projections influenced their current state. Hemingway (2011) suggested that temporality was closely related to care, which formed the basis of this study. Moreover, Leonard (as cited in Benner, 1994) described 'a priori' as a "…character of its state of being as one whose kind of being is care" (p. 54). Walsh (1995) argued that bracketing exists in interpretive phenomenology but instead uses a priori assumptions to seamlessly blend the researcher's approach and their experience. Where a priori assumptions serve as barriers in Husserl's descriptive practices, they are instead a way to reveal valuable presuppositions in the interpretive tradition. In this study, my history of providing care to this population of people and my commitment to facilitate improvement to this care established past and future contexts of temporality and my experiences guided my efforts toward being in time with participants.

With interpretive phenomenology well-aligned with both the purpose of my study and my experience in this area of practice, it was important to continue to stay true to the underpinnings of this philosophy when identifying a theoretical framework. Phenomenological inquiry relies on an emerging theoretical framework so as to avoid unduly influencing the lived experience of participants (Creswell, 2014; Lopez & Willis, 2004). Instead, theory is used implicitly to plan the methodology and as a conceptual, or orientating framework, but is much more explicitly present in the data analysis and thematic evaluation phases (Casanave & Li, 2015).

My experience with community-based eating disorder care has guided the identification and selection of the theory for this research study. The conceptual or orientating framework, for this study is Riegel, Jaarsma, and Stromberg's (2012) middle range theory of self-care in chronic illness. The major concepts of this theory include self-care management, self-care maintenance, and self-care monitoring; all of which apply directly to community-based eating disorder care, where treatment relies heavily on an individual's ability to manage their health. Riegel et al. (2012) said that the factors of experience, skill, motivation, culture, confidence, habits, support from others, and access to care influence an individual's ability to provide self-care. Use of these concepts and influencing factors in methodological planning and framing the interpretation of data, was intended to illuminate the participants' experiences and contextual elements that I aimed to understand in this study.

While this is a relatively new theory, it has been successfully used as a theoretical basis for the development of a tool to measure self-care in patients with Diabetes Mellitus

(Ausili et al., 2017). The focus of this study was significantly different in terms of both content and philosophical orientation; however, the findings provided an opportunity for further application of the theoretical model. Further, the use of Riegel, Jaarsma, and Stromberg's (2012) middle range theory of self-care in chronic illness in the research of Ausili et al., provides a rigorous example of application that was used to guide my use of this same theory to underpin my research.

Nature of the Study

The nature of this study was qualitative and was conducted using an interpretive phenomenological methodology. This phenomenological approach was used to explain experiences of young adults receiving community-based eating disorder care, as well as elucidate an introductory understanding of the community, nursing, male, and Canadian contexts. The interpretive, or hermeneutical phenomenological approach, was appropriate given my experience with community-based eating disorder nursing care, as the philosophies that underpin this approach place value on experience as an interpretive lens (Heidegger as cited in Flood, 2010). A critical research principle in hermeneutics is that researchers must interpret the narrative accounts of their participants based on previously constructed understandings of them (Conroy, 2003). The use of this approach helped to understand the relationship between the individual participant living with an eating disorder and his or her lifeworld (Lopez & Willis, 2004).

Given the inherent propensity to provide privacy, the generational appeal and comfort with such a method, as well as the growing use of this method in qualitative studies involving sensitive subject matter, asynchronous online focus groups were conducted for data collection (Harmsen, Mollema, Ruiter, Paulussen, deMelker, & Kok, 2013; Woodyatt, Finneran, & Stephenson, 2016; Zwaanswick & Dulman, 2014). Due to the sensitive nature of this study and the inherent vulnerability of individuals with eating disorders, participants were recruited from existing outpatient programs to ensure that they had access to appropriate health care monitoring during the study. As one goal of this research was to explore the geographical context of community-based eating disorder care within Ontario, Canada; participants were sought across the province. A private-access online forum was used for focus group discussion. Participants were strongly encouraged to hide their identity to protect their privacy in the online forum.

As conceptual saturation, or conceptual depth, is an iterative process, it was difficult to definitively plan the exact number of participants needed to achieve it in advance (O'Reilly & Parker, 2012). To satisfy Nelson's (2016) conceptual depth criteria of range, complexity, subtlety, resonance, and validity, I anticipated the need for 15-20 participants to achieve saturation. Data were collected and stored in a secure online forum where verbatim transcripts were taken and thematically analyzed using the constant comparison (Glaser, 1965) and Interpretive Phenomenological Analysis methods (Pietkiewics & Smith, 2014). Thematic analysis was done through hand-coding and did not require the use of qualitative electronic data analysis software.

Definitions

For the purposes of this research, the following definitions were utilized to represent the key concepts of the study:

Eating disorders: Defined by the American Psychological Association's (2013) Diagnostic and Statistical Manual for Mental Disorders' (DSM-5) criteria for Anorexia Nervosa (AN) and Bulimia Nervosa (BN).

Young adult: Individuals aged 18 to 22. As no standard definition of 'young adult' can be found in the literature, and due to the highly variable use of this term in published studies, this criterion has been influenced by the ages of patients set forth by the participating community-based eating disorder programs.

Community-based eating disorder care: Specialized eating disorder out-patient care, provided in whole, or in part, by nurses and received outside of a patient's home (Hickey & Hardyman, 2000).

Contextual elements: Defined as "…the dynamic and historical relationship between social structure and social action…" that is influenced by the following factors; (a) discourse, (b) policies, (c) institutional and network relations, (d) histories of relationships and interaction, and (e) activities and engagement (Harris and Rampton as cited in Murdoch, 2016, p.3). The aim of developing contextual elements is to derive knowledge and facilitate knowledge integration through improved understanding of purpose, resources, and constraints involving a phenomenon of interest (Scott & Hofmeyer, 2007).

Self-care: "A process of maintaining health throughout health promoting practices and managing illness" (Riegel, Jaarsma & Stromberg, 2012, p. 194).

Self-care maintenance: "Self-determined behaviors and/or mutually agreed upon behaviors proposed by health care professionals that are needed to achieve biopsychosocial balance in the chronically ill person’s life (Riegel, Jaarsma & Stromberg, 2012, p. 194).

Self-care monitoring: “The chronically ill patient’s assessment of their health status and includes both subjective and objective data (Riegel, Jaarsma & Stromberg, 2012, p. 196).

Self-care management: “The manner in which an individual reacts to their assessment findings in the self-care monitoring phase and influences engagement and empowerment (Riegel, Jaarsma & Stromberg, 2012, p. 196).

Assumptions

This research study was conducted based on several assumptions. The primary assumption in this study was that most individuals receiving community-based eating disorder care have been stigmatized and marginalized by the health care system during the course of their illness. It was also assumed that these experiences would motivate participants to share their stories for the collective purpose of improving eating disorder care and that in order to do so, individuals would be truthful and accurate in their focus group responses. Further, I assumed that participants met the inclusion criteria and that individuals who participates had rich information to share and were stable enough, physically and emotionally, to participate. To this end, I also assumed that participants continued to receive ongoing care from their health care professionals during their participation in the study.

Scope, Delimitations, and Limitations

The purposes of this study were to explore the lived experience of young adults receiving treatment for their eating disorder in the community and contextual elements involving community-based eating disorder care in Ontario. As the evidence addressing the experiences of young adults is most lacking, and due to the developmental differences inherent in these age groups, this study excluded children, adolescents younger than 18, and adults over the age of 22. Further, as no consensus on the definition of ‘young adult’ can be found in the published literature, the age group of participants for this study was determined based on the parameters set by the eating disorder treatment programs from which participants were recruited. All participants were required to read and write in fluent English and have self-supporting Internet access and comfort with an online chat forum. To produce data that would elucidate context, it was important to purposively recruit male patients and participants from across the province. Finally, the study was limited to only those with diagnoses of anorexia nervosa or bulimia nervosa. Other DSM-V eating disorder diagnoses were excluded due to the significantly different treatment plans for these groups.

Since recruitment fliers were displayed in eating disorder treatment centres across the province, only those programs with staff willing to post the fliers were included in the study. Further, only clients who self-reported that they were currently receiving care were recruited. As the intention was to explore the experience involving community-based treatment, only those programs offering outpatient services were deemed appropriate for recruitment. Several treatment programs across the province offer both inpatient and outpatient programs simultaneously, and since inpatient care is commonly a part of patients' treatment trajectories, participants were also recruited from these sites, as their perspectives offered valuable comparative data between delivery systems.

Several limitations were anticipated in this research study. First, the lived experiences of individual participants in this study cannot be generalized to a greater population but rather they can elucidate collective experiences in Ontario, Canada and be transferred to people with eating disorders all over the world. Next, sharing of participant experiences was limited to the written word, which does not always convey messages as completely or as clearly as face-to-face communication in qualitative research involving interviews or traditional focus groups. By allowing asynchronous participation in a group chat forum, participants were not limited by location, time, or space. Participants had the opportunity to interact with their peers for the purpose of idea generation and to stimulate continuance and depth of the conversation. Participants registered themselves on the online forum using their email account, which allowed me to contact them, where necessary, to validate findings and aid in triangulation and trustworthiness.

With reflexivity in qualitative research being important in trustworthiness, it is prudent for researchers to identify potential biases in advance of conducting research. As a Caucasian Canadian, heterosexual female in my early 40's, privileged by these factors and a middle-class upbringing, I had to acknowledge how these demographics may influence my interpretations in terms of gender, culture, history and socioeconomics. Further, my experience as a nurse practitioner in an adolescent eating disorders program inevitably shaped my interpretations of the data, resulting in researcher bias, however, I feel that the reflexive measures planned for this study allowed me to maintain a stance of empathic neutrality, or a judgement-free understanding that communicates authenticity, support, trust, and openness (Patton, 2015). There was potential for both acquiescence and social desirability biases in the discussion, however, these risks were mitigated by the anonymous online forum and due to the open-ended, non-leading nature of the interview questions.

Significance

This research has the potential to make a significant contribution to the body of nursing knowledge involving eating disorder care by nurses and the community setting. More specifically, this study has elucidated the perspectives of the recipients of this care, thereby providing valuable insights into the roles of nurses and the experiences involving outpatient care in the Canadian healthcare system that have yet to be explored in the published literature. Given that the Ontario government currently funds a community-based model of eating disorder treatment involving nurses and nurse practitioners (Ontario Community Outreach Program for Eating Disorders, 2017), it was imperative to establish an understanding of the patients’ perspectives to determine ongoing funding, underpin the philosophy of care, and inform future patient-centered interventions.

The findings of this study provided information about these experiences across political, economic, practice, and social change contexts. Learning about the patient perspectives in this study has provided foundational knowledge about community-based eating disorder care upon which additional research may be conducted. Generating more evidence about community-based eating disorder care can inform evaluations about whether existing protocols for eating disorder care established by non-nursing disciplines, inpatient treatment programs or other countries are appropriate for use in outpatient eating disorder care in Canada. There is potential that this research may establish the nursing role in eating disorder care from a new community-based context, which in turn, enhances the discipline.

Finally, the findings from this study will contribute to positive social change. By enhancing the understanding of community-based eating disorder care from the patient perspective, opportunities for additional inquiry may be created that are focused on patient priorities. New evidence may challenge or enhance current practices established by different disciplines or perhaps introduce nurse-specific interventions that can improve patient-centered eating disorder care and more appropriately guide the practice of nurses in this role. Establishing nursing's role in eating disorder care may further contribute to multidisciplinary approaches to eating disorder care that have been associated with improved outcomes for patients (Weltzen et al., 2014)). The findings of this study may also influence policy and funding, particularly in Ontario, Canada, where a nurse-practitioner-led model of care is currently in place despite having little published evidence to support this practice. Improving patient-centered eating disorder care within the community setting may be of fiscal benefit as in-patient treatment is more expensive and associated with even greater societal costs when the impact on caregivers is considered (Toulany et al., 2015). This research provided a forum in which individuals affected by eating disorders had opportunities to share their experiences in a dignified manner.

Summary

Eating disorders are serious illnesses that negatively impact quality of life and cause significant risk of morbidity and mortality (Mehler & Anderson, 2010). There is a paucity of evidence to support community-based eating disorder care in Ontario, Canada, although this is how treatment is currently funded and administered. Nurses working in community-based eating disorder care presently rely on evidence from other disciplines and settings to guide their practice. Little is known about patients' experiences involving care using this delivery model, and it is important to focus on their perspectives. The purpose of this interpretive phenomenological study was to gain an understanding of community-based eating disorder care from the perspective of young adult patients across Ontario and to elicit the contextual information regarding eating disorder treatments.

In Chapter 1, I presented an overview of the problem, as well as the purpose, supportive theoretical framework, significance, and potential limitations of this study. Chapter 2 includes a comprehensive review of the literature regarding community-based eating disorder care and the role that nurses play in this care as well as search strategies used to locate this literature. Chapter 3 includes design, methodology, and data collection strategies for this study. In Chapter 4, data from qualitative, asynchronous online focus groups are analyzed and presented. Finally, Chapter 5 addresses the interpretations of data and potential implications of findings.

Chapter 2: Literature Review

Introduction

In this chapter, I review and analyze the existing evidence addressing eating disorders in young adults in Canada and abroad as it pertains to care provided by nurses. Currently, eating disorder care is heavily influenced by medicine and psychology and by researchers in countries such as the United States and Australia, leaving the evidence established in different disciplinary and geographical contexts to guide the practice of Canadian nurses. Further, the small body of evidence addressing the nursing role is almost exclusively focused on inpatient eating disorder care. In Ontario, Canada, most care is provided on an outpatient basis, with only episodic hospitalizations for acute illnesses that result from eating disorders. The purpose of this interpretive phenomenological study was to gain an understanding of community-based eating disorder care from the perspectives of young adult patients in Ontario, Canada and to establish the context of nursing-focused community-based care in this province. Reigel, Jaarsma, and Stromberg's (2012) middle range theory of self-care of chronic illness was used as the orientating framework for methodological planning and analysis.

The existing research about inpatient eating disorder care established the role of the nurse as a beneficial and valuable addition to the treatment team (Tierney, 2008; Zugai, Stein-Parbury & Roche, 2012). There is evidence to support the cost-effectiveness of community-based eating disorder care (Rosling, Ros & Swenne, 2016; Sheridan & McArdle, 2016). Efficacy has also been established by both health care providers who provide and by patients who receive community-based eating disorder treatment

(Findlay, Pinzon, Taddeo, & Katzman, 2010; McCormack, Watson, Harris, Potts, & Forbes, 2013; Newton, Bosanac, Mancuso, & Castle, 2013; Ramjan, 2004). More specifically, patients who receive community-based eating disorder care report improved quality-of-life (Sheridan & McArdle, 2016) as well as psychopathology and functioning (Newton et al., 2013). Additionally, and addressing the care from nurses specifically, patients reported improved adherence and motivation for treatment (Tierney, 2008; Zugai, Steon-Parbury & Roche, 2012).

Literature Search Strategy

This literature review involved primarily peer-reviewed journal articles accessed through electronic databases, including MEDLINE with Full Text, CINAHL Plus with Full Text, PubMed, PsycINFO, PsychARTICLES, and ProQuest Nursing and Allied Health Source. Key words used for searching were *eating disorders, anorexia nervosa, bulimia nervosa, community-based eating disorder care, community-based eating disorder treatment, young adults, and Canadian eating disorder care.* Searches were limited to literature published between 2013 and 2020 and excluded *children* and *inpatient* search terms. However, due to the lacking literature found with this strategy, both exclusions needed to be expanded or removed on several occasions. Books and select dissertations were also used. Sources were then organized by key concepts into a literature review matrix, which guided the analysis of the theoretical framework, methodology, results, and implications.

Theoretical Foundation

Riegel, Jaarsma and Stromberg's (2012) middle-range theory of self-care of chronic illness was used as the orientating framework for this research study. This theory evolved from the care of adults with heart failure in the authors' nursing practice, as is typical of the development of middle-range theories and serves as a testament to the pragmatics of such theories (McEwen & Wills, 2014). The goal in creating this theory was to, "…codify the behaviors and processes used by individuals dealing with a diagnosis of chronic illness…" (Riegel et al., 2012, p. 4).

This theory was heavily influenced by Orem's grand theory of self-care but builds in a contextual orientation to chronic illness and presents a framework at a different level of abstraction. While Orem's theory was used to guide nursing care and explain nursing practice (Orem, 2004), Riegel, Jaarsma and Stromberg (2012) aspired for their theory to help multidisciplinary health care professionals to understand their role in facilitating patient self-care. Orem also focused her work on meeting the needs of nurses while Riegel, Jaarsma and Stromberg (2012) strived to focus directly on the chronically ill individual.

In the theory of self-care of chronic illness, self-care is defined as, "a process of maintaining health throughout health promoting practices and managing illness" (Riegel, Jaarsma & Stromberg, 2012, p. 5). By their definition, Riegel et al. purport that self-care is evident in both well and unwell states and therefore a chronically ill individual's ability to provide self-care fluctuates throughout time. As perceptions of health and illness are significantly variable in chronically ill individuals, so are their perceptions of self-care

(Rockwell & Riegel, 2001). As a result, the definition of self-care provided does not list specific tasks or abilities one must have to provide self-care, but instead, self-care is considered a highly individualized phenomenon.

Central concepts of this theory include self-care maintenance, self-care monitoring, and self-care management, which are all connected through the individual's chronic illness journey, yet do not necessarily flow in a linear pattern (Riegel, Jaarsma, & Stromberg, 2012). Self-care maintenance refers to the self-determined behaviors and/or mutually agreed upon behaviors proposed by health care professionals that are needed to achieve biopsychosocial balance for chronically ill individuals. Individuals determine the value afforded to each self-care maintenance behavior and this often is reflected in their adherence. An important consideration in this concept is the need for health care professionals to partner in care planning in order to help chronically ill individuals to balance their needs with the evidence-based therapies recommended to treat their conditions. Self-care monitoring involves the chronically ill patient's assessment of their health status and includes both subjective and objective data. Reigel et al. (2012) term this assessment, 'body listening,' and assert that recognition of change in chronic illness is the goal of self-care monitoring. The intention of recognizing change is that it initiates the decision-making process and prompts action. How the individual reacts to their assessment findings during the self-care monitoring phase constitutes their chronic illness self-care management. This process involves engagement in care and empowerment to address one's health.

The middle-range theory of self-care of chronic illness centers around the belief that self-care must be supported by caregivers and the processes of decision making and reflection (Riegel, Jaarsma, & Stromberg, 2012). The relationship between the caregiver and patient is of important influence to an individual's self-care abilities, particularly with respect to motivation and adoption. The concept of naturalistic decision making, or the, "…automatic, impulsive, contextual decisions that people make in complex real-world situations," (Reigel et al., 2012, p. 9). The dynamics of such a process, particularly when one considers the complexity added by one or more chronic illnesses, is highly influential in an individual's self-care outcomes. Finally, an individual's ability to self-reflect is considered closely related to their self-care outcomes. Riegel et al. (2012) describe ideal self-care as being best facilitated by the attributes of reflectivity, purposivity, sufficiency and reasonability. While individual abilities to provide self-care may lie at variable points on the self-care continuum, it is an individual's understanding of their abilities, through the process of reflection, that more closely correlates to self-care management outcomes.

With eating disorders being chronic illnesses, often characterized by lengthy and pernicious courses, and causing both mental and physical health problems, the theory of self-care of chronic illness is applicable. While my anecdotal experience as a Nurse Practitioner working with adolescents with eating disorders helped me draw many similarities between my patients' experiences and this theory, it is the assumptions and propositions of the theory that demonstrate the strongest alignment to my study. The assumptions refer to the subjective and highly externally influenced nature of chronic illness. Moreover, Riegel, Jaarsma and Stromberg (2012) expound on the notion that multiple chronic illnesses experienced at once can add further complexity. This is certainly true with eating disorders considering that most of the individuals afflicted have co-morbid psychiatric illness (Aspen et al., 2014; Zaider, Johnson & Cockell, 2000) and when you consider the contextual element of chronic illness in the young adult age demographic, the complexity of these individuals' chronic illness perceptions becomes even more dynamic. Next, Riegel and colleagues described how challenging it can be for non-reflective individuals to achieve successful self-care and this applies very much to the element of denial evident in most people at some point in eating disorder illness (Williams & Reid, 2012). In response, they assert that reflective self-care can be learned and perhaps this can frame the transition of dependency in illness to more independent direction toward wellness that often characterizes the trajectory of eating disorder treatment (Stewart & Williamson, 2004). An explicit proclamation of this theory suggests that self-care is only feasible for those who can make judicious decisions, and during the acute periods of eating disorder illness, individuals are not able to engage in self-care due to their cognitive limitations secondary to malnutrition. A major goal in treating eating disorders is to stabilize an individual as quickly as possible so that they can engage in self-care and sound, independent decision making (Guillaume, Gorwood, Jollant, Van den Eynde, Courtet & Richard-Devantoy, 2015). Finally, the proposition that lack of knowledge most commonly contributes to insufficient self-care highlights the importance of the communication and relationship between care provider and patient. Reflecting on my own experiences with eating disorder patients, I have seen how a strong therapeutic relationship can support a patient’s decisions, ultimately facilitating greater self-care during the recovery journey. Although the Theory of Self-Care of Chronic Illness is well-aligned with this research study, it has not been applied specifically to eating disorders research within the published literature. However, the concept of self-care has been addressed in several eating disorder contexts.

Self-care has been studied in the prevention and psychological care of eating disorders but there is no published literature about its role in community-based nursing care. Cook-Cottone (2016) has studied the role of self-care both in the prevention of eating disorders and in the treatment of body image disturbance. Drawing from her previous phenomenological research examining the mind-body connection, Cook-Cottone (2016) hypothesized that eating disorders can be prevented if children can be proactively taught to appreciate their bodies and embody self-regulatory and self-care skills. To promote these skills, this author recommended mindfulness and yoga-based practices in what is termed a “top-down, bottom up… integrative approach…” toward self-care as a protective measure (p 101). Further to these thoughts on how self-care should form the basis of preventative care, Cook-Cottone (2015) also recommended self-care as a treatment modality for those who have body image disturbance or eating disorders. She referred to this treatment as *mindful self-care*; a process involving foundational work needed to achieve both physical and emotional health through self-awareness and compassion, self-soothing, spirituality, and medical care of the physical self.

The concept of self-care has also been researched as an outcome of cognitive behavioral therapy (CBT) in eating disorders. While self-care was not the direct focus of any of the research, several studies exist where other interventions were evaluated that gleaned insight about the notion of self-care in eating disorders. Schmidt et al. (2008) studied the efficacy of self-care focused CBT in participants with Bulimia Nervosa or Eating Disorder Not Otherwise Specified (EDNOS) with primary purging symptoms. Although the findings were inconclusive, there were some initial symptomatic improvements noted with guided self-care CBT therapy, leaving the authors to conclude that further inquiry into the role of self-directed interventions in eating disorder treatment was warranted. In another study, Schmidt et al. (2006) found that personalized feedback throughout the course of self-care CBT resulted in a reduction of purging and restricting symptoms. In another study, Schmidt et al. (2007) compared the efficacy of self-care focused CBT for treating adolescent Bulimia Nervosa compared to Family-Based Treatment, the current gold-standard of care for this age group (Findlay, Pinzon, Taddeo & Katzman, 2010). Findings included greater efficacy of self-care focused CBT due to its rapid symptom reduction, lower cost, and patient preference. While this research cannot substantiate a conclusive preference of young people for self-care, the findings elude to the potential for an alignment between self-care and the developmental desire for young adults to achieve control.

There is scant published research addressing the concept of self-care relating to young adults, while there is a great deal that addresses self-care in adolescents. As the age parameters that define adolescent and young adult in several studies overlap, I will draw from both sets of evidence here. Martorell-Poveda, Martinez-Hernaez, Carceller-Maicas, and Correa-Urquiza (2015) studied self-care strategies to contend with emotional distress among adolescents and young adults aged 17-21 in Spain. They found that the participants felt responsible for their own distress and therefore responsible for dealing with it. This was further compounded by their developmental strive for self-sufficiency. While fueled by autonomy, participants sought help from family and friends to facilitate their efforts. Martorell-Poveda et al. (2015) questioned how this translates to young adults seeing help from health care professionals to improve their self-care skills and concluded that until this question is explored in the literature, it is critical for health care professionals to respect the self-sufficiency and autonomy of young adults. Sawicki, Kelemen and Weitzman (2014) examined the role of self-care in the transition from pediatric health services for adolescents to adult health systems. They found that approximately 70% of young adults and their parents believed that the young adult could manage their care in the adult health system, yet only a small percentage of both participants and parents had a plan to transition from pediatric to adult services. In several dyads, high levels of confidence in self-care skills were incongruently correlated to low levels of transition preparedness, leading Sawicki et al. to conclude that the facilitation of self-care skills is necessary for the successful transition of adolescents to adult health services. Canty-Mitchell (2001) explored the role of hope in the self-care agency of inner-city adolescents aged 13-19. In her study, hope was viewed as a power, a coping ability, a life meaning, and a protective mechanism; all of which translate to the nature of eating disorders. In fact, Mansfield and Wade (1999) found that hopelessness was a common characteristic of thought in eating disorders and when controlling for depression, findings demonstrated that hopelessness was experienced differently in depressed individuals with eating issues compared to those depressed persons without. The findings in Canty-Mitchell's (2001) study revealed strong correlations between hope and self-care agency; specifically among the subscales of ego strength, awareness of feelings, and health knowledge, which support the previous recommendations of Martorell-Poveda, Martinez-Hernaez, Carceller-Maicas and Correa-Urquiza (2015) for partnered care, Sawicki, Kelemen and Weitzman (2014) for preparedness and education, and finally, Cook-Cattone (2015) for mindfulness in young adult self-care agency.

Literature Review Related to Key Concepts

Eating Disorders

Eating disorders are a set of mental illnesses that cause significant burden to those who are afflicted by them and include several physical complications, along with social, emotional, functional, economic and even community impairment (Hart, Granillo, Jorm, & Paxton, 2011). Quality of life for people with eating disorders is poor and impairment rises with the severity of illness (DeJong et al., 2013). Most individuals with eating disorders also have co-morbid psychiatric illness, particularly anxiety and depression, but many more also suffer from personality disorders, substance abuse, self-injury, and trauma (Aspen et al., 2014). It is this combination of diagnoses paired with mental and physical health challenges, the cognitive effects of malnutrition, and the resistant nature of the illness that makes eating disorders challenging to treat (Aspen et al., 2014; Innes, Clough & Casey, 2017; Mattar, Huas, Duclos, Apfel & Godart, 2011).

Incidence and prevalence. The incidence of eating disorders in Canada is estimated to be between 1.5 and 3% which equates to between 725,800 and 1,088,700 people (National Eating Disorder Information Centre, 2014; National Initiative for Eating Disorders, 2017). In an Ontario-focused large-scale community study of individuals aged 15-65, the lifetime prevalence of full syndrome Anorexia Nervosa was 0.56%, with partial-syndrome illness at 1.4% and a rate of 1.1% for Bulimia Nervosa (National Initiative for Eating Disorders, 2017). Prevalence of eating disorders was 2% for males and 4.8% for females in Ontario (National Initiative for Eating Disorders, 2017). By comparison, the lifetime prevalence for Anorexia Nervosa and Bulimia Nervosa in the United States was estimated to be 0.8% and 2.6% respectively in a large 8-year community study of American women aged 12-15 (Stice, Marti & Rohde, 2012). The greatest incidence of eating disorders in Ontario was found in girls aged 10-12 years and was estimated at 9.4 cases per 100,000-person years (National Initiative for Eating Disorders, 2017).

It is likely that these statistics grossly underestimate the number of individuals who have eating disorders. When you consider that eating disorders are characterized by shame and secrecy, it is likely that these statistics are limited by self-reports and/or mis-diagnosis/under-diagnosis. In a population-based study of eating disorder behaviors, the National Initiative for Eating Disorders (2017) found that over 50% of girls and over 30% of boys engaged in unhealthy behaviors such as fasting, vomiting, laxative abuse, skipping meals and smoking as an appetite suppressant in an effort to control their weight. In another community sample within southern Ontario, researchers found that

27% of girls aged 12-18 reported significant eating disorder symptoms however, only 6% of these individuals had ever received any assessment or treatment for these symptoms (National Initiative for Eating Disorders, 2017). Moreover, only 1.6% of the total sample had ever been evaluated for their eating behaviors.

Despite the common perception that eating disorders affect only white, affluent, female teenagers, the reality is that these diseases do not discriminate (Cohn, Murray, Walen & Wooldridge, 2016). They affect all economic, social, age, and ethnic groups as well as all genders/sexes. Hudson, Hiripi, Pope and Kessler (2007) suggest that males constitute 25% of all Anorexia Nervosa and Bulimia Nervosa cases and these numbers would be further increased if sub-clinical cases were also included (Mond, Mitchison & Hay, 2014). The most concerning data to date is that for the first time, the rate of male eating disorder cases is rising more quickly than cases in females, possibly indicating improved access to treatment and reduced stigma (Cohn et al., 2016). Conversely, the Public Health Agency of Canada (2003) reports that ratios of girls to boys with eating disorders is 5:1 in childhood but in adolescence and adulthood this ratio increases to 10:1. This may imply that stigma in adolescence and adulthood serves as a barrier to diagnosis and treatment for males with eating disorders. Males are often underdiagnosed, despite demonstrating the same concerning symptoms as their female counterparts (Vo, Lau & Rubinstein, 2016).

Eating disorders also affect individuals who identify as lesbian, gay, bisexual, transgender and questioning (LGBTQ) in disproportionately high numbers (Brown & Keel, 2012). For example, Cohn, Murray, Walen and Wooldridge (2016) report that gay men represent as high as 42% of men in treatment for eating disorders. A lean and muscular body type is often culturally idealized which has been shown to cause body dissatisfaction and reduced quality of life in gay men (Griffiths, Murray, Dunn & Blashill, 2017).

A final population that disproportionately experiences eating disorders is with elite athletes. Sungot-Borgen and Torstveit (2004) found that 20% of female and 8% of male elite athletes met eating disorder criteria compared with 9% ad 0.5% of their respective matched controls. Those whose sports involved weight classes and endurance requirements were at greater risk. At even greater risk were, female athletes in aesthetic sports such as figure skating, gymnastics and dance.

Types of eating disorders. In the most current edition, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) has classified eight major eating disorders; Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, Pica, Rumination Disorder, Avoidant/Restrictive Food Intake Disorder (ARFID), Unspecified Feeding or Eating Disorder (UFED), and Other Specified Feeding or Eating Disorder (OSFED) [American Psychological Association (APA), 2013]. Each condition includes a list of criteria with which clinicians use to diagnose. This study includes only those meeting the diagnostic criteria for Anorexia Nervosa or Bulimia Nervosa.

The APA (2013) recommended a diagnosis of anorexia nervosa when an individual meets the following criteria:

1. Persistent restriction of energy intake leading to significantly low body weight with consideration of age, sex, development and physical health

2. Either an intense fear of gaining weight or of becoming fat, or persistent behavior that interferes with weight gain when weight is significantly low
3. Disturbance in the way one’s body weight or shape is experienced, undue influence of body shape and weight on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight

Several sub-types of Anorexia Nervosa exist and may also be included in this study. These include (a) Atypical Anorexia Nervosa that involves all of the diagnostic criteria for Anorexia Nervosa but the individual affected has not experienced weight loss and may even be overweight, and (b) Purging Sub-Type which includes self-induced vomiting (APA, 2013).

The experience of having Anorexia Nervosa is characterized by struggles for control, changes in identity and a love-hate relationship with the disease (Williams & Reid, 2012; Tierney, 2008). In their phenomenological exploration of the relationship between individuals and their eating disorder, Williams and Reid (2012) found that participants collectively experienced both positive and negative aspects of Anorexia Nervosa. More specifically, participants characterized Anorexia Nervosa as both a friend, that offered support, reassurance and purpose, as well as an external entity that wreaked havoc and was difficult to achieve freedom from. As a result of this dualistic relationship, Anorexia Nervosa became a means to achieve the perfect self through control but when individuals became too emotionally and physically compromised, that control was completely lost, allowing the disease to take over and resulting in a loss of self.

In a study of Anorexia Nervosa treatment, Tierney (2008) described this phenomenon as, ‘the individual within a condition.’ Tierney’s focus on the person prompted her to conduct a qualitative study of the experience of treatment. Findings from this study reveal the need for access to appropriate care, a balance of physical and psychological intervention, as well as understanding and support from family, friends and professionals. In their mixed methods study of the treatment experience for anorexic patients, Fogarty and Ramjan (2016) similarly found that the most important aspects of treatment were being understood, being presented with hope for the future, and gaining self-acceptance. Moreover, empowered treatment that helped an individual cope with change was associated with greater commitment to treatment and motivation.

The DSM-5 diagnostic criteria for Bulimia Nervosa, according to the APA (2013) includes:

1. Recurrent episodes of binge eating, characterized by eating an amount of food that is definitely larger than most people would eat in a short period of time and under similar circumstances, along with a sense of lack of control over eating during consumption.
2. Recurrent inappropriate compensatory behaviors in order to prevent weight gain including self-induced vomiting, misuse of laxatives or diuretics, fasting or excessive exercise.
3. The binge eating and inappropriate compensatory behaviors both occur on average, at least once per week for three months
4. Self-evaluation is unduly influenced by body shape and weight

Despite several shared symptoms, the experience of having Bulimia Nervosa has been found to be quite different than the anorexic experience. In a phenomenological exploration of Bulimia Nervosa, Broussard (2003) revealed a great deal of isolation and fear because of the secret binge/purge behaviors. Further, bulimic patients reported the same internal struggle to give and take back power from their eating disorder that anorexics reported; however, this struggle typically gave way to binging behaviors, that spawned feelings of guilt, which in turn, perpetuated the cycle further. The women in this study reported that their attempts to achieve balance were most often achieved by getting rid of fullness and guilt about eating through purging, although many of them also reported guilt after purging as well. The cycle of guilt caused by binging and purging resulted in those with Bulimia Nervosa having the highest degree of functional impairment and the poorest quality of life (DeJong et al., 2013).

Shame, secrecy, and stigma were also strong findings in other studies. Pettersen, Rosenvinge and Ytterhus (2014) refer the bulimic experience as living a ‘double life,’ where individuals affected were trying to maintain the appearance of a functional, productive life while working equally hard to conceal the bulimic behaviors they characterized as shameful. In examining the psychology of the double life phenomenon, these authors poignantly describe Bulimia Nervosa as a “…volitional exertion of interaction control, not just a result of poor impulse regulation” (p. 204). In examining recovery from Bulimia Nervosa, Lindgren, Enmark, Bohman and Lundstrom (2014) found that self-efficacy, the antithesis of shame and self-deprecation, was necessary. Self-acceptance was the skill that facilitated readiness for change and movement away from

Bulimia toward a new reality and identity. These authors report that to achieve this change, those with Bulimia Nervosa had to accept help, find the strength and courage to do the work to build self-esteem, learn how to cope with challenges and learn to value themselves. Like the notion that illness is both a friend and coping mechanism found in the review of Anorexia Nervosa and Bulimia Nervosa literature, all participants in this study who achieved recovery reported strong ambivalence about leaving their eating disorder behind.

Treatment barriers. Several treatment barriers have been identified in the literature. In their systematic review of primarily adults seeking eating disorder treatment, Innes, Clough, and Casey (2017) identified stigma, poor mental health literacy, perceived need for treatment, negative past treatment experiences, low motivation and service restrictions as barriers identified across several studies. These authors also reported how challenging it was to draw comparisons between the barriers identified in qualitative studies on account of their variability. This finding supports the notion that treatment barriers are often highly unique to the individual and refers to how other factors such as geography and access to various health care services would be influential on the treatment experience. Thompson and Park’s (2016) literature review offered support for several of these barriers but also elucidated several new insights. These authors found several studies that addressed how health beliefs, particularly about severity, risk perception, and past experiences, influenced treatment access. Social stigma was also addressed in the ways that patients with eating disorders concealed them, which in turn, challenged their treatment and access to information about their illness. Personality traits-specifically impulsivity, perfectionism and emotional regulation- also served as barriers to treatment. Financial barriers were also discussed within an American context. While this information is not directly applicable to Canada's socially funded health care system, eating disorder patients in Ontario without additional supplemental private insurance experience less access to important services such as psychology, than their insured counterparts do. Access in Ontario is also challenged by the vast geographical space of the province in comparison to the proximity of treatment centers, which are typically situated in metropolitan areas, similar to the way treatment centers are located across the United States (Thompson & Park, 2016). A final barrier addressed in this literature review involved the perceptions of physicians. Physicians receive inadequate training about how to manage eating disorders and as a result, can misdiagnose or underdiagnose the condition, and inadequately assess for and manage potential associated complications (Thompson & Park, 2016). The National Initiative for Eating Disorders (2017) reported that 70% of Canadian physicians received 5 hours or less of eating-disorder specific education and/or training in medical school. Additionally, only 6.3% of psychiatry residents felt that they had adequate education to work effectively with eating disorder patients (National Initiative for Eating Disorders, 2017). While these data do not address the perceptions of other health care professionals, there may be similar misconceptions about and experiences with eating disorders within these groups that also contribute to barriers to treatment.

Barriers also exist that are inherent to both ethnic and age minorities seeking eating disorder treatment. Cachelin and Striegel-Moore (2006) found that Mexican-

American women with eating disorders sought treatment less often and were less likely to receive a diagnosis or treatment than their European American female counterparts, even after both groups endorsed the same barriers. Regan, Cahelin and Minnick (2017) conducted a systematic review of barriers to initial treatment and found that older individuals are more likely to seek out initial treatment than younger adults. Some studies also found that duration of illness was often longer in treatment-seeking individuals which may correlate to age. These are concerning findings given that the total number of individuals seeking and receiving eating disorder treatment is significantly low; only 1 in 10 people affected (Government of Canada, 2006) potentially leaving adults and/or minorities without the care they require.

Course of illness. In their year-long prospective study of adolescent eating disorder symptoms, Hautala et al. (2008) found several factors that contribute to the persistence of disordered eating. These factors included higher body mass, greater body dissatisfaction, and the thin-ideal internalization. These authors also found that female participants, and those who were depressed, also experienced persistent disordered eating. Hautala and her colleagues hypothesized that several of the adolescents they identified with disordered eating would likely revert back to more normalized eating patterns had participants been re-assessed at a second interval, however, given their additional finding of early-onset anxiety as a precursor to disordered eating, these authors suggested screening for co-morbid disordered eating when this symptom is noticed in youth. In their study of women with Anorexia Nervosa and Bulimia Nervosa, Harrison, Tchanturia, Naumann and Treasure (2012) found additional characteristics that may have contributed to the onset and the persistence of eating disorders. It was discovered that participants with eating disorders, both past and present, often demonstrated perseverative cognitive styles; a thought pattern by which people are unable to modify their thinking in response to contextual translation. The stronger the association was to this cognitive style, the more profound and lengthy the course of the eating disorder was found to be. Conversely, the control group, made of up mentally and physically well participants with no eating disorder history or behaviors, most often demonstrated global flexible cognitive styles. These authors suggested that their findings support the existing evidence that identifies inflexibility and social emotional disturbance as contributing factors to the maintenance eating disorders and that treatment should focus on both cognitive and social emotional skill building.

While research estimates that only 60% individuals in eating disorder treatment will recover (Anorexia Nervosa and Related Eating Disorders, 2016), there is no consensus on the definition of recovery (de Vos, LaMarre, Radstaak, Bijkerk, Bohlmeijer & Westerhof, 2017), thereby leaving a cohort of people with chronic illness, many of which include young adults. Noordenbos, Oldenhave, Muschter, and Terpstra (2002) identified that individuals with eating disorders lasting longer than ten years are often left out of research, and have difficulty seeking treatment due to the thought that they are incurable. To capture the effects of eating disorders on patients' lives and reflect the influence of age, Noordenbos et al (2002) expressed the duration of eating disorders as percentage of their lives spent with an eating disorder. Their findings demonstrated that all patients had spent between one third and sixty percent of their lives with the disease.

During this time most participants reported that their eating disorders caused physical ailments such as malaise, dizziness, insomnia, and chronic pain, as well as social problems in the form of isolation, family issues, and job loss. In the group of participants with the shortest duration of illness, the average age of onset was 21, compared to the group with the longest duration whose average age of onset was 15-years-old; a finding that substantiates previous evidence suggesting that onset of an eating disorder at a young age is associated with a poorer prognosis. It is estimated that approximately 20% of patients diagnosed with an eating disorder will develop long-term illness and experience higher mortality rates as a result.

Morbidity and mortality. Eating disorders are associated with many medical and psychiatric complications that can cause significant morbidity and may also be fatal. Katzman (2005) identified cardiac diseases such as bradycardia, hypotension, valve dysfunction, pleural effusion, and arrhythmias, as the most common and serious medical complication in Anorexia Nervosa. Growth impairment is another complication that can lead to dysfunction of several hormones and bone density loss. Self-harm and co-morbid psychiatric illness result in significant morbidity and a large number of deaths by suicide. Finally, risk even exists for those undergoing nutritional rehabilitative treatment with the potential complication of refeeding syndrome. Severely malnourished individuals are at risk for this syndrome when they begin to eat and drink again due to severe fluid shifts which cause significant changes in electrolytes that are needed for effective cardiac, neurological and hematological function.

While the same medical complications exist for those suffering from Bulimia Nervosa, there are some complications that arise from purging and laxative abuse that are unique. Purging is associated with acid reflux, dental erosion, stomatitis, gingivitis, esophageal disease and inflammation/swelling of the salivary and parotid glands (Mehler, 2011). Laxative abuse can cause dangerous electrolyte imbalances or severe gastrointestinal issues. Diuretic abuse is also associated with electrolyte dysregulation.

Another important consideration in the morbidity of eating disorders is that cognition, and resultant decision making, is challenged in patients secondary to malnutrition. Clinical consensus about this relationship has long been conferred anecdotally, however, the evidence to justify this assertion is inconsistent. Mattar, Huas, Duclos, Apfel and Godart (2011) suggested that this is likely due to the heterogeneity of participants, small sample sizes, inconsistent use of psychometric scales and comparison of results across Anorexia Nervosa and Bulimia Nervosa populations within the research examining the cognitive effects of malnutrition. Katzman (2005) concurs that there are structural and functional brain changes that result from eating disorders but suggests that further research is needed to better understand how these changes affect cognition.

In their 15-year study of mortality in a large sample of Germans receiving inpatient eating disorder treatment, Fichter and Quadflieg (2016) found that circulatory collapse, cachexia, organ failure and suicide were the most common causes of death. Their findings indicated that the number of deaths peaked in the 25-34 age group of anorexics, thereby suggesting an increased mortality risk in young adults with Anorexia Nervosa. Those with Anorexia Nervosa were found to have a five times higher rate of death than age-matched healthy controls. Individuals with Bulimia Nervosa also had a higher mortality risk than the rest of the population in their age group, however, it was not as high as the risk with Anorexia Nervosa. The results indicated no significant difference in mortality rates between men and women. The most significant predictor of shorter time to death in both Anorexia Nervosa and Bulimia Nervosa was premature discharge from treatment, which has important implications for inpatient and outpatient eating disorder treatment. Other predictors of shorter time to death included lack of supports, chronicity of illness, prior suicide attempts, and the severity of symptoms.

In a cohort study of adults in British Columbia, Canada, the standardized mortality ratio for anorexia nervosa was calculated at 10.5 with a life expectancy reduction of 20-25 years (National Initiative for Eating Disorders, 2017). For comparison, the standardized mortality ratio calculated in a US-based community sample was 5.9 for anorexia nervosa and 1.9 for bulimia nervosa (Stice, Marti & Rohde, 2012). The standardized mortality ratio from suicide for anorexia nervosa in the Canadian study was 4.7 and was significantly increased to 6.5 for bulimia nervosa. Morbidity rates for both anorexics and bulimics in this study were found to be higher than healthy controls based on the variables of eating pathology, functional impairment, emotional distress, and suicidality.

Eating Disorders and Young Adults

The literature exploring the experience of young adults with eating disorders was limited, however, there was a moderate body of evidence addressing the experiences of adolescents. There was also a substantial amount of literature addressing adult eating disorders. However, with adulthood most often being defined in these studies from 18 years and older to the mid-70's, there is great variability of applicability to the young adult cohort. In fact, the Canadian Pediatric Society position statement on age limits of adolescence defined an adolescent as being in the developmental period, "… roughly…between the ages of 10 and 19 years" (Canadian Pediatric Society, 2003, p. 577) and this range corresponds to the literature on children, adolescents and adults. In order to best address the young adult cohort, the literature from both adolescents and adults must be reviewed and will be presented here.

While Canadian statistics indicate that risk factors for eating disorders such as dieting, teasing about weight, negative body image and poor self-esteem begin in childhood, there is evidence to say that these issues persist into adolescence and adulthood (Loth, MacLehose, Bucchianeri, Crow & Neumark-Sztainer, 2014; National Initiative for Eating Disorders, 2017). In a large cohort study of British Columbia students, researchers found that 80% of girls meeting the criteria for normal height and weight, stated that they wanted to weigh less by the age of 18 (National Initiative for Eating Disorders, 2017). Heavy social media use in adolescents has been associated with constant social comparison and resultant negative body image (Kalnes, 2013). The result is a majority population of adult females who transition to adulthood with body image disturbance. In fact, prevalence rates of Anorexia Nervosa and Bulimia Nervosa increase during the transition from adolescence to adulthood (Hoek, 2007; Liechty & Lee, 2013).

The transition from adolescent to adult eating disorder treatment is often challenging, particularly since there are no existing guidelines that address how to best support patients during this time (Winston, Paul & Juanola-Borrat, 2012). Slane, Klump, McGue and Iacono (2014) conducted a longitudinal study of disordered eating, focusing on Bulimia Nervosa, in female twins from the ages of 11 to 25. Findings from this study indicate that disordered eating, body dissatisfaction, and weight pre-occupation increased from age 11 to the age of 25 with bulimic symptoms peaking at 18 and stabilizing by the age of 25. Slane, Klump, McGue and Iacono (2014) suggested that body image, more so than disordered eating, may be the primary issue in young adulthood and should therefore be considered in prevention and treatment efforts. Other studies have found that disordered eating decreased in young adulthood (Heatherton, Mahamedi, Striepe, Field, & Keel, 1997; Keel, Fulkerson & Leon, 1997) or reported that symptoms stabilized during this time (Dolan, Evans, & Lacey, 1992; Keel, Baxter, Heatherton & Joiner, 2007). This variability could reflect individual reactions to the transition from adolescence to adulthood or perhaps reflect the nature of treatment being received.

Dimitropoulos et al. (2015) studied a group of young adults, aged 17-21, who were transitioning from adolescent eating disorder care to adult treatment. These authors' decision to conduct this study was prompted by their concern that adolescents with eating disorders would experience feelings of loss and fear similar to findings from studies examining transition to adult treatment in mental health care and other types of care. Findings from their qualitative study indicate that young adults did experience inconsistent care which contributed to several barriers to recovery, Participants' suggestions to improve this transition included the following, (a) more partnered adolescent care to prepare for the increase in autonomy in adult care, (b) more direct communication early in the discharge planning process, (c) education for patients and families about the differences in adolescent and adult care, (d) a greater focus on emotional care in adult treatment as opposed to physical care, and (e) clearer communication about expectations at discharge given that several participants believed that discharge from adolescent services indicated recovery despite ongoing symptoms. Additionally, is was discovered that many health care professionals perceived young adults as developmentally and psychologically immature and that they lacked the skills and decision-making capability to navigate adult care; which Dimitropoulos et al (2015) felt had significant implications for clinical practice in adult eating disorder care.

A final consideration in the transition from adolescent to adult eating disorder care is the availability of services. In her paper reviewing eating disorder care in young people, Burton (2014) reported that services are often reduced or eliminated once young people reach adulthood. In Ontario, there are fewer community-based adult eating disorder services and the amount and variety of adult in-patient services are even less available [Ontario Community Outreach Program for Eating Disorders (OCOPED), n.d.]. Several of the mental health facilities that specialize in eating disorder treatment do not accept patients over 18 (OCOPED, n.d.). Given the evidence suggesting that medical and psychological outcomes are poorer in adults whose eating disorders persist into midlife (Ackard, Richter, Egan & Cronemeyer, 2014), and the increased incidence of mental illness at midlife in young adults with disordered eating (Herpertz-Dahlmann, Dempfle, Konrad, Klasen & Ravens-Sieberer, 2015), it is important to focus on the efficacy of treatment in adolescence and young adulthood.

Tailoring treatment to the needs of patients with eating disorders has also been explored in the literature. Sheridan and McArdle (2016) explored the treatment preferences of young adults from a motivational perspective using a self-determination theoretical framework. Their findings revealed a strong significance placed on the environment in which treatment is being delivered. Participants expressed preference for residential treatment over hospital treatment because it better reflected the environment in which they would return to during out-patient treatment. Young adults in the study also indicated a preference for a treatment culture that shifted focus from illness to recovery and emphasized the value of connectedness with their treatment providers. By comparison, Zugai, Stein-Parbury and Roche (2013) found that adolescent in-patients shared many of the same preferences. These participants also valued aspects of ‘normal life’ and felt that their nurses’ attempts to have fun and make them feel like “…regular people…” contributed significantly to the therapeutic alliance and hospital experience (p. 2024). Above all other preferences, however, participants valued caring most. Perceptions of caring most often involved discussions and/or actions of respect, trust, support, motivation, and insight. Ballard and Crane (2015) advocated for treatment to align with age. These authors found that treatment for individuals 55 and older was less expensive and shorter than any other age group, followed by the second lowest cost to treat in the 44-55 age group. While treatment in these age groups have a lower treatment cost, the societal financial and individual quality of life burdens into middle-age suggest the need to treat more aggressively in adolescence and young adulthood. Findings also demonstrated that adults have higher dropout rates and lower rates of returning to care afterward; thereby indicating the likelihood of barriers unique to adults that prohibit care and the need for retention efforts to keep younger adults in treatment.

The Role of Nurses in Eating Disorder Treatment

There is strong evidence to suggest that a multidisciplinary approach to eating disorder care is important (Findlay, Pinzon, Taddeo, & Katzman, 2010), however, the role of the nurse within this team is less understood. In a case study presentation of a newly established multidisciplinary eating disorder unit in a Colorado hospital, Breiner (2003) discussed the nurse's role within the team as being dualistic. While nurses were expected to provide care for the patients' medical needs, they were also expected to address their emotional needs, which were often complex and beyond the scope of the nurses' practice. Nurses on the unit expressed frustration with this and in response, a child life specialist was hired and the entire team received training in addressing the two primary emotional needs of anxiety and fixation on media images of beauty. Two particular interventions; serial body tracing/analysis and feelings mask painting, were found to be beneficial means of distraction and symptom reduction to staff and patients. While the findings from this study cannot be generalized to a wider population, they highlight the imbalance of knowledge and expectation that nurses face while working in eating disorder care and support the need for training and collaboration in multidisciplinary care.

Low job satisfaction among nurses working in eating disorder care is concerning. Raveneau, Feinstein, Rosen and Fisher (2014) found that only 6.3% of nursing and medical staff on an inpatient eating disorder unit found their job satisfying or rewarding.

Additionally, almost 70% of the staff felt frustrated and over 40% felt helpless when asked about the care they provided. While empathy scores were higher in nurses than in physicians, only 50% felt empathetic for their patients and only 12.5% felt rewarded by their caregiving. Staff in this study reported lack of knowledge, lack of team support, inconsistency in care, poor communication, and staff turnover as influencing factors. While these alarming findings can be reflective of institutional and systems-level problems, they also highlight the negative impact of limited education for health care professionals (Thompson & Park, 2016), lack of standardized clinical practice guidelines (Canadian Agency for Drugs and Technologies in Health, 2011), and the paucity of research addressing the role of the nurse in eating disorder care (Snell, Crowe, & Jordan, 2010).

Findings of low empathy, poor job satisfaction, and frustration may indicate caregiver burnout. Eddy (2013) explored burnout in eating disorder therapists and reported that emotional exhaustion and having a patient die are the most common precursors to burnout. Additional contributing factors to the experience of burnout in eating disorder professionals were chronic worry about the patients, high rates of relapse, and a lack of knowledge regarding the patients' medical problems (Eddy et al., 2015), lack of experience/training and one's own weight (Warren, Schafer, Crowley & Olivardia, 2013). Protective factors included working in the outpatient setting, having children and having a personal history of an eating disorder (Warren, Schafer, Crowley & Olivardia, 2013). While therapists in the study by Eddy et al. (2015) experienced distress about their lacking medical understanding, the opposite may be true for nurses and their lack of knowledge and skill to provide psychosocial care (Raveneau, Feinstein, Rosen & Fisher, 2014; Seah, Tham, Kamaruzaman & Yobas, 2017). Thompson and Park (2016) identified a significant void in eating disorder education in medical school, and if this same gap exists in nursing education, this fundamental lack of knowledge may also contribute to nurses' distress. In fact, Kass et al. (2015) suggested that what nurses are taught in school may in fact be counter-intuitive and detrimental to the care of eating disorder patients. For example, nurses are taught to facilitate healthy weights in their patients according to psychometric measures such as body mass index (BMI), however this practice has been linked to negative body image and disordered eating (Kass et al., 2015).

Ryan, Malson, Clarke, Anderson and Kohn (2006) said that the most commonly reported perception of nurses involved with eating disorder care is that the care is particularly challenging. This may be attributed to the denial that often accompanies both diagnosis and treatment and can lead to patients exhibiting uncooperative or challenging behavior (Raveneau, Feinstein, Rosen & Fisher, 2014; Seah, Tham, Kamaruzaman & Yobas, 2017; Treasure & Schmidt, 2001). Newell (2004) described the power struggle that can occur when nurses respond to such behaviors with implementing additional controls and the resistance they receive in response from patients who are desperately trying to re-gain control. Furthermore, nurses may find their values conflicted in the care of eating disorder patients. In a phenomenological exploration of nurses' experiences conducted by King and de Sales Turner (2000), one participant shared that her inherent trust in children was very conflicted due to the manipulative behaviors common in eating disorders, resulting in moral distress about being cynical of pediatric patients. Thompson-Brenner, Satir, Franko, and Herzog (2012) as well as Seah, Tham, Kamaruzaman, and Yobas (2017) reported that negative reactions to eating disorder patients were very common among health care providers. This finding conflicts with the needs of eating disorder patients and may further contribute to the challenging nature of eating disorder treatment.

In studies examining patient preferences for health care providers, an approachable, empathetic, empowering, positive individual was viewed as the most therapeutic (Fogarty & Ramjan, 2016; Sheridan & McArdle, 2016; Zugai, Stein-Parbury & Roche, 2012). In examining the small amount of literature specifically addressing the nursing role in eating disorder care, there is great consistency and emphasis on the value of the therapeutic nurse-patient relationship. Eating disorder patients have described their nurses as loving, empathetic, necessary for surveillance, constant, and ever-present (Ryan, Malson, Clarke, Anderson & Kohn, 2006). Van Ommen, Meerwijk, Kars, van Elburg and Van Meijel (2008) found that nurses played a significant role in providing and maintaining structure, ensuring responsibility, and helping frame patients' inpatient treatment as normalized. Snell, Crowe and Jordan (2009) discovered that nurses felt their primary role was connecting. More specifically, nurses felt responsible for developing the therapeutic connection, negotiating its boundaries and fostering its continued strength in order to facilitate successful treatment for their patients. Interestingly, the concept of maternalism strongly emerged from Wright's (2015) phenomenological study of the therapeutic nurse-patient relationship in eating disorder care. The attributes needed for nurses in eating disorder care, from both patients' and their own perspectives, could arguably be related to maternalism. In examining the history of nursing from a feministic perspective, there is a logical connection between the historical, but timeless caring role of the nurse and treatment of young eating disorder patients who aspire for maternalistic care.

Community-Based Eating Disorder Treatment in Canada and Across the World

In the 1980's and 1990's, eating disorder treatment was offered primarily on an inpatient basis across the United States. However, Wiseman, Sunday, Klapper, Harris and Halmi (2000) described a significant shift to community-based treatment leading up to the turn of the century which they attributed to less availability of insurance coverage for hospitalization with the influx of health maintenance organizations (HMOs), the rising cost of inpatient care, and an evolved philosophical orientation to eating disorders as chronic illnesses. With these changes came a 25% reduction in length of hospital stay between 1988 and 1992, an increase in the number of transfers from acute care to supervised community residencies once medical exacerbations were stabilized. The National Institute of Clinical Excellence (2004) now recommends specialized outpatient treatment for eating disorders whenever possible.

While there is no published literature to support similar trends in Canada, the advent of a group to provide training to outpatient providers across Ontario in 1994, roughly coincides with the American shift to community-based eating disorder care. Funded by the Ontario Ministry of Health and Long-Term Care, the Ontario Community Outreach Program for Eating Disorders (OCOPED) is a multidisciplinary group of professions committed to the provision of specialized services to individuals with eating disorders (McVey et al., 2005). Their membership is comprised of professionals who work in inpatient units, hospital outpatient programs or non-hospital-based community health organizations. Between 1995 and 2002, OCOPED facilitated eating disorders education for more than 4,000 health care professionals across Ontario that provided training in the areas of assessment, enhanced outpatient treatment, day treatment, inpatient care and/or prevention, depending on each site's needs (McVey et al., 2005). The provincial network is based on a hub and spokes approach, whereby geographical areas of the province will have a hospital primary care center offering inpatient and often outpatient services and several additional facilities who offer outpatient care and in some cases, smaller-scale inpatient services. The intention of this approach is to improve accessibility for those who live outside of large metropolitan areas where more services are offered. For example, in Southwestern Ontario, London Health Sciences Center is the primary site with several smaller programs in the surrounding areas of Windsor, Chatham, and Sarnia. Community-based care is offered in each area; however, patients are required to travel to London if specialized acute care eating disorder services are available beyond what their local hospital can offer in terms of medical and/or psychiatric stabilization. McVey and her colleagues concluded that the provincial training program, aided by ongoing funding from the Ontario government, would support change at the systems level to support community-based eating disorder service delivery. No literature evaluating the efficacy of the Ontario community-based eating disorder program was found in the published literature.

In rural Australia, where access to metropolitan eating disorder services was limited, a very similar training program was initiated for health care professionals in the area (McCormack, Watson, Harris, Potts & Forbes, 2012). In fact, 90% of psychiatric and eating disorder services are located in large cities across the country, requiring rural citizens to either travel great distances or seek health care from their existing health care professionals, who are not always confident or skilled in these specialties. Over one year, education was delivered at no cost to over 500 multidisciplinary care providers, along with ongoing consultation, support, and collaboration by two experienced facilitators. Following training, the health care professionals reported improved perceived capacity to manage eating disorders.

Service delivery. Similar to the variability of eating disorder programming across the world, there is no consistent approach across Canada. In a study examining 11 adolescent eating disorder specialty programs across Canada, Norris et al (2013) reported very diverse program leadership strategies, governed by either psychiatry, pediatrics, or a combination of the two, as well as variable team structure, funding sourcing, referral processes, reporting protocols, and treatment guidelines. Due to the absence of sufficient eating disorder services, three Canadian provinces could not even be included in this study. There was more consistency in the multidisciplinary team approach, the need for both inpatient and outpatient services at each site, and the availability of Family Based Therapy. These findings led the researchers to conclude that the lack of standardized approach has implications for clinical practice, health policy, funding and patient care.

Several settings have been utilized for community-based eating disorder care. In Britain, Coombs (2011) described the provision of eating disorder assessment, referral and care co-ordination through school nurses. Cooper et al. (2017) provided web-based training to therapists across Canada and the United States to prepare them to work with eating disorder patients. They found that web-based training was efficacious and that the effects of training were sustained as the newly educated therapists began to work with patients. These authors suggest that this method be studies on a greater scale to determine the potential for more widespread education that can improve access for patients. Thorne (1995) described the role that nurses and physicians can play in eating disorder and mental health care in Canadian university campus health centers. Finally, Clinton, Almlof, Lindstrom, Manneberg and Vestin (2014) piloted a new delivery model in an existing adult outpatient facility in Sweden. To address the concerns of accessibility and wait-listing, these authors examined the experience of being treated on a drop-in basis to specialized services and found that participants felt this delivery model offered freedom of choice, security, and increased motivation. While the responses may also be attributed to the open philosophy of care at the study facility, these results demonstrate important considerations for how eating disorder patients prefer to access services.

Eating disorder treatment has previously been addressed as a challenging care modality. In a large mixed-methods study of nurses and physicians, Linville, Benton, O’Neil and Sturm (2010) found that community health care professionals were very cautious and hesitant about participating in eating disorder care. There were several characterizations of eating disorders as overly complicated, too dangerous, or simply too “messy” (Linville, Benton, O’Neil and Sturm, 2010, p. 120). Several participants indicated that young, critically ill people were intimidating and others stated that they felt like there was nothing they could do to help people with eating disorders. All participants in this study cited ignorance about eating disorders and lack of training in school as a barrier to providing care. Robinson, Boachie, and Lafrance (2013) had similar findings when they investigated the perceptions of competence in Canadian physicians and psychologists. Self-assessments of competence were low and lack of skills and resources as well as the acuity and complexity of eating disorder illnesses were identified as contributing factors. Most of the participants identified education and training as opportunities to better assess, treat, and prevent eating disorders.

Patients are also concerned about the experience and confidence in their health care providers. In her phenomenological inquiry into the experiences of adolescents receiving treatment for Anorexia Nervosa, Tierney (2008) found that healthcare providers who were underconfident could be easily manipulated by patients. Several participants recalled encounters with trainee and new staff members who believed their assertions that everything was fine when really they were engaged in eating disorder behaviors. Others cited that some providers were apathetic, overly authoritative or/and lacking sensitivity; responses felt to be associated with stigmatization. Instead, participants expressed desire to be treated by providers who challenged the irrational part of their illness in a non-judgmental manner while maintaining supportive care.

In addition to the challenges presented by stigmatization, community-based eating disorder care has been plagued by inconsistent use of evidence-based care. Firstly, there are few standardized care guidelines available for use by nurses in eating disorder care (Winston, Paul & Juanola-Borrat, 2012). Those in existence have been created for inpatient treatment and were established to guide medical and psychological practice. Despite several of the discipline's eating disorder treatment protocols being standardized, Von Ranson, Wallace, and Stevenson (2012) report that there is significant inconsistency in their application to community-based care across Alberta, Canada. They reported that several evidence-based treatments have been found to be highly under-utilized in several studies across the world. Like the contextual challenge faced by nurses in the community, the dynamics of this out-patient treatment setting are not adequately understood in psychology either, making practices derived from inpatient treatment difficult to apply in other settings. Research examining the barriers to using evidenced-based practice in psychology have found that professionals feel that they are too rigid to apply to their complex eating disorder patients. Further, those who were involved in research or are regular consumers of research were more likely to employ evidence-based strategies which may better explain the findings given that most psychologists in Alberta are practicing at the master's level. Most participants were not specialized in eating disorder care, prompting the researchers to consider lacking confidence and/or knowledge as possible contributing factors.

In Canada, outpatient Family-Based Treatment (FBT) is considered the standard, and most effective, treatment for children and adolescents (Findlay, Pinzon, Taddeo, & Katzman, 2010). Norris et al. (2013) suggested that FBT is used quite consistently across the country in child and adolescent intensive eating disorder care. In this modality, parents assume responsibility to restore their child’s weight in their own home while a multidisciplinary team provides medical monitoring, therapy and support in specialized outpatient clinics. The intention of outpatient FBT is to keep the patient connected with their family, friends and activities to yield long-term recovery. While there is strong evidence to support FBT in the care of adolescents with eating disorders, it has not been adequately studied in young adults, in those without available/supportive families, or in non-specialized medical facilities such as primary care (Findlay et al., 2010).

Utilization. The current state of health care utilization in eating disorders can be considered paradoxical in several respects. Those with eating disorders access health care significantly more than their non-affected counterparts, however, most are not receiving the treatment they require (Hart, Granillo, Jorm & Paxton, 2011). In fact, most patients seeking health care do not receive eating disorder or mental health treatment, but instead are assisted with weight loss (Mond, Hay, Rodgers & Owen, 2007). The National Initiative for Eating Disorders (2017) found that time from onset of illness to accessing effective treatment took an average of 10 years for Bulimic individuals and 15 years for those with Anorexia. With so few people with eating disorders receiving timely and appropriate treatment for their illness (Dalle Grave, 2011), coupled with high drop-out rates and low responsiveness to treatment (Waller, 2012), there is an urgent need to examine the utilization of community-based eating disorder treatment.

Waller et al. (2009) examined utilization of adult eating disorder treatment at the referral, assessment, treatment, and discharge phases. They found that 35% of those referred were never seen, only 50% of those assessed entered into treatment, and only

25% of those who entered treatment reached program discharge. These findings are concerning from a health care utilization perspective but may also be attributed to the stigmatized and secretive nature of eating disorders, or the scarcity of available resources. They are also concerning when considering that improved prognosis is associated with early reduction of eating disorder symptoms.

It is challenging to engage eating disorder patients enough to enter into treatment, but it is even more challenging to keep them engaged long enough to achieve recovery. With motivational and trust issues commonly accompanying eating disorders, patients often move in and out of treatment (Waller et al., 2009). Baiden, den Dunnen and Stewart (2013) found that adolescent mental health inpatients, including those with eating disorders, often discharged themselves from treatment against medical advice (DAMA). Younger age, male gender, shorter length of stay, substance abuse history and eating disorder or personality disorder diagnoses were identified as contributing factors to DAMA. Those who are discharged against medical advice, are significantly more likely to be re-hospitalized compared to those who were discharged by their care providers. The authors assert that an improved understanding of DAMA may inform early interventions to maintain patients in treatment. Wallier, Vibert, Berthoz, Huas, Hubert, and Godard (2009) also examined drop-out from inpatient eating disorder care and found great variability in the findings of research examining this phenomenon, prompting them to conclude that drop-out is an important, yet poorly understood consideration in eating disorder treatment.

Time is another important factor in eating disorder care. First, the typical trajectory of care must be considered. The average duration of treatment is 8.3 years (Hudson, Hiripi, Pope, & Kessler, 2007) but some receive treatment for periods far longer. Noordenbos, Oldenhave, Muschter and Terpstra (2002) identified chronic eating disorders as those lasting ten years or longer and reported that 1 in 5 new onset eating disorders will progress to a chronic duration. These authors found that the mean age of their participants with chronic duration was 34 and that these individuals had suffered with the illness for an average of 15.2 years. Sadly, most participants in this study viewed themselves as incurable, having endured treatment, with varying degrees of success and ongoing symptoms, for many years. Additionally, participants shared that their diagnosis was delayed, and that they often felt unsupported by their care provider. Participants also stated that specialized eating disorder care was the most comprehensive and helpful. The exclusion of adults from eating disorder research has been a recurrent problem discussed previously in this literature review and Noordenbos et al. (2002) suggest that this is why little is known about the nature of chronic eating disorders.

Wait-lists for treatment are of concern to both patients and healthcare providers. MacNeil, Nadkarni, Leduc, and Leung (2016) suggested that wait-times for adult eating disorder inpatient care in Canada are very lengthy due to the limited facilities across the country that offer these services. For example, these authors identify only 20 publicly funded beds for adults across Ontario; a province with a total population of 13.4 million people (Statistics Canada, 2016). Wait times are even more concerning given that extended periods of time without intervention have been shown to decrease motivation and commitment to treatment. In response to prolonged wait times, these researchers arranged for a severely ill anorexic adult patient to receive intensive multidisciplinary outpatient treatment while she awaited inpatient therapy. Over a period of six months, she gained 4.5 kilograms of weight and no longer met the criteria for inpatient admission.

It is important to explore the impact of length of stay and re-admission rates in eating disorder treatment. In their analysis of inpatient adult psychiatric care in Ontario, Stewart, Kam and Baiden (2014) found that eating disorders were a strong predictor of a longer hospital stay but that they did not predict re-admission. Substance abuse and mood disorders, both of which are commonly associated with eating disorders, influenced longer stays as well. It may be possible that the low rates of re-admission may have been influenced by reduced motivation during time spent on a waiting list (MacNeil, Nadkarni, Leduc & Leung, 2016) or perhaps, reflective of the perception of incurability experienced by those who experience chronic illness into adulthood (Noordenbos, Oldenhave, Muschter & Terpstra, 2002).

While awaiting inpatient service and/or during community-based treatment, individuals with eating disorders often access primary care and emergency services as well. In their study of adolescent risk behavior in primary care in Ontario, Byrne et al. (2004) found that the youth who were at greatest risk were afraid to visit their primary care provider yet were high users of crises services. The authors suggested that crisis services were a reactive approach and instead advocated for more proactive care through the establishment of therapeutic relationships with specialized outpatient eating disorder professionals. Mond, Hay, Rodgers and Owen (2007) found that adult patients seeking community-based eating disorder care, on the other hand, most often do so from their family physician, indicating the potential for primary care to facilitate eating disorder care and suggesting that this care pathway is more accessible to adults. Dooley-Hash, Lipson, Walton and Cunningham (2013) found that patients with eating disorders across the age spectrum utilized emergency department services at a rate of 1.6 times higher than patients without eating disorders. Interestingly, the most common chief complaint was non-emergent abdominal pain and other gastrointestinal complaints unrelated to their eating disorder, which could best be managed in primary care. It may be possible that the traditional business hours of primary care practices prohibit eating disorder patients from accessing services during their times of need, leaving them no choice to attend an emergency room that offers services 24 hours per day. Dooley-Hash, Lipson, Walton and Cunningham's (2013) study did not offer any rationale for the participants' decisions to visit emergency services, nor did they indicate the timing of such visits.

Cost

Cost is an important factor in outpatient eating disorder treatment. Toulany, Wong, Katzman, Akseer, Steinegger, Hancock-Howard, and Coyte (2015) found that the average 37.9-day inpatient stay for eating disorder treatment amounted to a total hospital cost of $51,349 Canadian dollars and a total societal cost of $54,932 Canadian dollars, accounting for individual and family members' missed work time, and costs of commutes, parking and productivity. Hospitalization costs were higher for those with lower BMIs and a 15.7% decrease in cost was noted for each unit increase in BMI. Previously, MacNeil, Nadkarni, Leduc, and Leung (2016) advocated for intensive outpatient therapy to keep those waiting for inpatient treatment safe. Another benefit of this strategy is to facilitate weight restoration as an outpatient in order to lower inpatient costs and possibly eliminate the cost altogether if admission is avoided.

Further contributing to the economic burden of eating disorders in Ontario is the practice of supporting patients financially to receive care in other countries. de Oliveira et al. (2016) estimate the cost of out-of-country eating disorder care at 5 million dollars annually and for those who receive additional adjunct care within Ontario that cost rises to 11 million dollars per year. Most individuals who are approved for such care often travel to private treatment facilities in the United States when their needs are too complex, or when waiting times are too long to receive appropriate care in Ontario. The researchers advocated for these monies to be re-focused into building capacity to deliver similar care in the future within the province.

In a systematic review of cost- effectiveness studies in the prevention and treatment of eating disorders, Le, Hay, and Mihalopoulos (2018) found that there were significant increases in these types of studies in recent years, suggesting an increased aware of the economic and personal burdens of these illnesses. Plagued by lacking methodological rigor and inconsistent findings, the authors reported that no value-for-money conclusions could be made. In a previous systematic review of eating disorder costs, Stuhdreher et al. (2012) also reported an increased number of economic studies as well as inconsistent findings and issues of methodological trustworthiness. However, they did report that all studies indicated that eating disorders come at a significant cost of both a direct and indirect nature, however several factors made the results difficult to compare.

For example, several American studies used insurance costs as a measure, yet other countries used pay-for-service costing or government funding as a measure. They suggested that more consistent measures of cost be used in future research to establish stronger conclusions and more generalizable findings.

Weissman and Rosselli (2017) conducted a final review of economic eating disorder burden. While they too, reported inconclusive findings, their analysis yielded two new conclusions. First, they discovered that significant financial costs were incurred to individuals, their families, and society. They also reported that there has not been a cost-analysis completed in the public sector. This is consistent with Lightfoot's (2016) dissertation study examining the perceptions and attitudes of public health officials with respect to eating disorders. In this study, participants did not see eating disorders as a significant problem and therefore, they did not monitor them. Specific reference to the cost of community-based eating disorder care was not addressed in any cost-related systematic reviews, however, with the cost of hospitalization being the greatest expense (Weissman & Rosselli, 2017), it may be assumed that outpatient care is less expensive.

Efficacy

Following a systematic review of treatment outcomes, Gowers and Bryant-Waugh (2004) concluded that community-based treatment was equally efficacious as is inpatient treatment for eating disorders. Most patients with anorexia nervosa and bulimia nervosa are treated as out-patients with the exception of those experiencing acute complications requiring hospitalization. Newton, Basanac, Mancuso and Castle (2013) reported that specialized eating disorder services positively impacted treatment outcomes. In their evaluation of a newly developed community-based specialty eating disorder program in Victoria, Australia, these authors compared body mass index, depression, anxiety and eating disorder symptoms pre- and post-treatment in the specialty program and discovered that most participants gained weight and experienced reduced symptoms from their eating disorders and co-morbid mental illnesses. Although this study was limited by the high attrition rate at the 1-year follow-up assessment, the results demonstrate efficacy, at least in the short-term. Rosling, Ros and Swenne (2016) also evaluated these variables in a one-year study of females with Anorexia Nervosa and Eating Disorder Not Otherwise Specified in Sweden. Of the 29 anorexic participants, 6 no longer met the diagnostic criteria at follow-up, all had gained weight, and 93% were back in school full-time.

Several other variables have been studied to measure efficacy of community-based treatment, although establishing the community context was not the focus in any research found. In a study of eating disorder patients receiving treatment in an out-patient clinic in Italy, Tomba, Offidiani, Tecuta, Schumann and Ballardini (2014) examined the impact on psychological well-being. Using several valid and reliable standardized tools, these researchers found that those with eating disorders scored lower in terms of psychological well-being than healthy controls in the areas of autonomy, environmental controls, positive relationships, and self-acceptance. Quality of life has also been used as a measure of efficacy in community-based eating disorder care. Mitchison, Dawson, Hand, Mond and Hay (2016) conducted qualitative research examining quality of life in a community sample of women who had a current or past eating disorder. Participants identified quality of life as both a factor that made them vulnerable to their eating disorder but also as a measure of recovery. Following treatment, participants noted that they experienced increased satisfaction, emotional maturation, new insights about their health, and developed more positive relationships; all if which they attributed to an improved quality of life. Finally, Hannon, Eunson and Munro (2017) conducted a qualitative study in a sample of women with severe Anorexia Nervosa receiving intensive outpatient treatment in Scotland. Participants ranged from those with significant medical complications to others with few symptoms or sequela. An interesting finding in this study was how the concept of change emerged in interviews with all participants across the spectrum of severity. More specifically, participants discussed the ideal of change but the difficulty of leaving the illness behind in order to achieve it. There were several comments that eluded to community-based care, with its slower pace, more partnered care philosophies, and the security of one’s home, as a modality more conducive to supporting change.

Summary and Conclusions

Eating disorders are serious illnesses of a mental and psychological nature and associated with high morbidity and mortality rates (DeJong et al., 2013; Katzman, 2005; Mattar, Huas, Duclos, Apfel & Godart, 2011; Mehler, 2011). Two common eating disorders, anorexia nervosa and bulimia nervosa, have been associated with significant functional, economic and community impairment among individuals, families, and societies (Hart, Granillo, Jorm & Paxton, 2011). Eating disorders are challenging to treat on account of the resistant and secretive nature of the illness, stigma, the lack of confidence and education of healthcare professionals to provide treatment and disease chronicity. The onset of eating disorders is typically in childhood or adolescence and persists into adulthood, with approximately 20% of cases becoming chronic (Loth, MacLehose, Bucchianeri, Crow, & Neumark-Sztainer, 2014).

The evidence to guide treatment of young adults with eating disorders is often drawn from research conducted with children and/or adolescents, despite adults expressing different preferences for treatment, care needs, and barriers to access (Dimitropoulos et al., 2015; Sheridan & McArdle, 2016; Slane, Klump, McGue & Iacono, 2014). The scarcity of resources available for patients aged 18 and older is a confounding problem (Burton, 2014). Adults seeking eating disorder treatment desire partnered and autonomous care that allows them to maintain a normal life (Zugai, Stein-Parbury & Roche, 2013).

With patients expressing preference for health care providers who are respectful, trustworthy and supportive (Zugai, Stein-Parbury & Roche, 2013), nurses may be ideal caregivers, however, their role in eating disorder treatment has not been adequately studied. Wright (2015) identified that the therapeutic nurse-patient relationship was highly valued by both nurses and patients. Heathcare professionals in these important roles however, experience high rates of job dissatisfaction and symptoms of burnout (Eddy, 2013; Raveneau, Feinstein, Rosen & Fisher, 2014; Seah, Tham, Kamaruzaman & Tobas, 2017).

Eating disorder care has shifted from an acute care, hospital-based model to a community-based model of care in response to fiscal restraint and changing philosophies

(Wiser, Sunday, Klapper, Harris & Halmi, 2000). Outpatient care is standard across the world, reserving short-term, and more costly, inpatient treatment only for medical complications (National Institute for Clinical Excellence, 2004; Toulany, Wong, Katzman, Akseer, Steinegger, Hancock-Howard & Coyte, 2015). Despite the intention of community-based treatment to bridge several barriers to access, most patients with eating disorders do not receive the care they require (Dalle Grave, 2011) and a large majority of those who seek care, drop-out (Waller et al., 2009), discharge themselves against medical advice (Baiden, den Dunnen & Stewart, 2013), endure lengthy wait-lists (MacNeil, Nadkarni, Leduc & Leung, 2016), or enter into a chronic phase where individuals often believe they are incurable (Noordenbos, Oldenhave, Muschter & Terpstra, 2002). Efficacy of community-based treatment has been established in terms of reduced eating disorders and mental illness symptoms (Newton, Basanac, Mancuso & Castle, 2013; Rosling, Ros & Swenne, 2016), improved psychological well-being (Tomba, Offidiani, Tecuta, Schumann & Ballardini, 2014), and improved quality of life (Mitchison, Dawson, Hand, Mond & Hay, 2016).

In Chapter 3, I will review the research design and methodology with description and rationale. Procedures for recruitment, participation, data collection and data analysis will be discussed. Finally, procedures to maintain both ethical research standards and trustworthiness will be presented.

Chapter 3: Research Method

Introduction

The purpose of this study was to gain an understanding of community-based eating disorder care from the perspective of young adult patients in Ontario, Canada and to establish the context of nursing in community-based care. An interpretive, phenomenological approach was used. Asynchronous online focus groups were used for data collection as they allowed for sampling across more of the province, had generational appeal, facilitated more critical thought, and offered comfort while discussing a particularly sensitive topic (Boydell, Fergie, McDaid & Hilton, 2014; Bruggen & Willems, 2008; Skelton, Evans, LaChenaye, Amsbary, Wingate & Talbott, 2018). To maintain methodological and philosophical alignment, an interpretive phenomenological analysis method, involving multiple readings, note taking, transforming notes into emergent themes, seeking relationships, and clustering themes, was used for data analysis (Pietkiewicz & Smith, 2012).

Reigel, Jaarsma, and Stromberg's (2012) middle range theory of self-care of chronic illness was used as an orientating framework for methodological planning and during the data analysis phase. More specifically, the focus group questions and research purpose were aligned with the central concepts of Reigel, Jaarsma, and Stromberg's (2012) theory. The decision to utilize asynchronous online focus groups was also influenced by this theory's concepts of self-care maintenance, self-care monitoring, and self-care management. Due to the flexible access of an online modality, participation did not interfere with patient appointments and therapy sessions, thereby facilitating self-care maintenance. Self-care monitoring was achieved by giving participants the time and privacy to self-reflect, along with the protection of privacy due to the asynchronous and anonymous nature of the online focus groups. Finally, asynchronous online focus groups offered participants the opportunity to participate in any environment and be engaged outside of their treatment environment. Allowing for this self-determined participation was in keeping with the tenets of self-care management whereby chronically-ill individuals assume responsibility for handling their own care.

In this chapter, I detail my methodological plans including participant selection, instrumentation, and procedures for recruitment, participation, and data collection. The researcher role, data analysis plan, and measures to ensure trustworthiness are also discussed. Lastly, ethical procedures planned to protect human subjects are presented.

Research Design

The central research question for this study is the following: What are the lived experiences of young adults receiving eating disorder care in the community? This research question uses the syntax of qualitative, phenomenological inquiry (Creswell, 2009) and is philosophically aligned with the purpose of interpretative phenomenological inquiry (Tuffour, 2017). Interpretive phenomenology is an appropriate methodology for this study due to the common goal of seeking to understand the participants’ thoughts, beliefs, perceptions, and experiences through immersion in their world (Benner, 1994). Furthermore, my experiences as a nurse practitioner providing eating disorder care has prepared me to immerse myself as a researcher in this area of inquiry and adhere to the hermeneutical principles for research (Conroy, 2003). These principles include the following: (a) entering into active dialogue with the population, (b) making explicit the shared views between the researcher and participants, (c) drawing out what is hidden within narrative accounts and interpret based on prior understanding, (d) engaging active focus group participation among participants, (e) working with participants to determine relevant and meaningful data, and (f) looking beyond the participants' words in terms of larger contexts and relationships to events (Conroy, 2003, p. 11).

Role of the Researcher

In this study, my role as the researcher was to communicate with participants, facilitate asynchronous online focus groups, analyze the data, and report the findings. I did not have any personal or professional relationships with the participants; however, I do have long-distance working relationships with some of the employees working at several outpatient clinics and through OCOPED. Since these health care professionals only posted recruitment fliers, my professional relationships with them in no way involved establishing power over participants. I notified participants of my background as an eating disorder nurse practitioner to establish trust.

Since my experience with this population inevitably creates researcher bias, I managed this by maintaining an analytic memo or journal throughout the research process as a bracketing measure (Ravitch & Carl, 2016). I also called upon my dissertation committee for member checking as external auditors to manage researcher bias. These individuals have varying degrees of a priori knowledge involving the phenomenon of interest and therefore were able to provide objective perspectives.

Finally, I triangulated the findings by examining the narratives of the two focus groups using the constant comparison method.

Methodology

Participant Selection Logic

Participants for this study were intended to include male and female young adults between the ages of 18 and 22 currently receiving community-based treatment in Ontario for anorexia nervosa or bulimia nervosa. Recruitment fliers were distributed via email to all health care professionals working in the eating disorder field in Ontario by OCOPED. The letter used to contact eating disorder health care professionals through OCOPED can be found in Appendix A, the recruitment flyer in Appendix B, and a sample letter of cooperation for potential participants who visit the online forum and complete the questionnaire may be found in Appendix C. For any organizations that required formal agreements to be drawn up in order to post recruitment flyers, I planned to connect with the appropriate authorities within those organizations.

Purposeful sampling was used to identify information-rich participants who provided an in-depth understanding of the phenomenon (Creswell, 2014; Patton, 2015; Ravitch & Carol, 2016). Interested participants accessed the web site listed on the recruitment flyer, where they were given basic details of the study. If they wished to participate, they were required to complete a brief survey to ensure they meet the inclusion criteria (age between 18-22, diagnosis of anorexia nervosa or bulimia nervosa, comfort with and access to the Internet, fluency in written English, and current status of receiving treatment for their eating disorder). Potential participants were asked to provide their city location and a brief description of how comfortable they were discussing eating disorder treatment in the online environment (see Appendix E). In the event that more participants met the inclusion criteria than are required for the intended sample, participants were planned for selection based on the following criteria: (a) comfort in discussing a sensitive subject matter in an online forum, (b) time availability, and (c) history of at least 12 months of out-patient treatment experience. To ensure a desired sample of 15-20 participants was achieved, slight oversampling was also planned. In the event that too few participants expressed interest or met inclusion criteria, a maximum of two follow up emails would be sent out to eating disorder professionals through OCOPED. If this effort failed to produce the desired sample size, snowball sampling would be employed through emailing the selected participants to request they share the recruitment flyers with other contacts. These individuals would then contact me via email to express their interest in participating, and I would screen them for inclusion criteria. Snowball sampling would also be used in the event that thematic saturation was not achieved with the desired sample.

Once participants are selected for participation, they were emailed the password-protected link to the online discussion board and were then able to communicate directly with the researcher in this forum. All necessary information about the study, including focus group ‘netiquette’ guidelines (Boydell, Fergie, McDaid, & Hilton, 2014) and consent forms were available in this forum and participants were able to ask questions and communicate any concerns to the researcher there. While I used an online forum with security measures in place to protect access to the data, nothing online can ever be fully secure and this was clearly communicated to participants.

Determining conceptual saturation is an iterative process and requires researchers to continuously evaluate their data (O’Reilley & Parker, 2002). This study used conceptual depth criteria of range, complexity, subtlety, resonance, and validity to determine saturation (Nelson, 2016). To satisfy the research purposes and achieve saturation, this study was thought to require between 15 and 20 participants. While this number is higher than most interpretive phenomenological studies call for (Mason, 2010), several participants from each site were required to provide experiential context. Geographical context was also explored in this study given that participants were recruited from across the province of Ontario.

Instrumentation

The instrument used to collect data in this study was the asynchronous online focus group forum. This method allowed for group discussion amongst young adult participants and the researcher, that would not be possible face-to-face due to the distance between us. Hatch (2002) advocated for online focus groups because they offer the opportunity to interview several individuals at once and gain their individual responses to research questions but also create valuable additional data through discussion among participants. Other benefits of online focus groups include automatic transcription, immediately available data, cost-effectiveness, participatory comfort, and more honest responses/critical thought about sensitive subjects from participants (Boydell, Fergie, McDaid, & Hilton, 2014; Bruggen & Willems, 2008; Skelton, Evans, LaChenaye, Amsbary, Wingate & Talbott, 2018). Fox, Rumsey and Morris (2007) found that online focus groups were helpful in reducing inhibitions based on youths' perceptions of physical appearance in face-to-face focus groups. Although there is no evidence to support their use in eating disorder research, these individuals are highly attuned to physical appearance and would likely find face-to-face focus groups and interviews challenging as a result.

The discussion prompts for the asynchronous online focus groups were developed by the researcher. Questions were established using the current research question and purpose as well as gaps identified in the literature review. The intention of this was to build an understanding of the previously reviewed literature from the participants' perspectives (Rubin & Rubin, 2002). The nomenclature, syntax, content, and context of these questions were aligned with Reigel, Jaarsma, and Stromberg's (2012) Middle Range Theory of Self-Care of Chronic Illness and can be found in Appendix D.

Procedures for Recruitment, Participation, and Data Collection

I conducted two focus groups; half of the participants (7-10) were in one group and the remaining participants were in another. This size was recommended to elicit the best group discussion over time (Reisner et al., 2017). The discussion prompts were the same in both groups. The use of multiple focus groups is recommended to avoid large numbers which can be challenging to moderate (Reisner et al., 2017). Additionally, this method offered opportunities for comparison between groups and was recommended for triangulation purposes (Onwuegbuzie, Dickinson, Leech & Zoran, 2009).

The focus groups were to be open for a period of two weeks and I provided daily moderation and facilitation. It was important to keep the focus group open long enough to allow participants the time to reflect and provide quality responses but not too long when several participants will drop-out (Boydell, Fergie, McDaid & Hilton, 2014). Bruggen and Willems (2008) suggested that the moderator of online focus groups leads the group, asks questions, clarifies any ambiguous statements, summarizes the discussion and ensures that all research questions are addressed. Participants had access to the focus group 24 hours per day during the 14-day period. Participants were asked to sign a consent form to confer their understanding that all information collected during the focus group will be confidentially maintained, and that participation was voluntary and could be withdrawn at any time and for any reason. If participants chose to withdraw and additional participants were needed, the researcher planned to send a follow-up email through OCOPED to seek further recruitment. If thematic saturation was not achieved after the desired sample has participated in the asynchronous online focus group, another round of recruitment using snowball sampling would occur and a second focus group would be arranged.

Once the focus groups have concluded, the researcher provided a thank-you letter via email to all participants. This letter explained the remainder of the research process. It also indicated how results may be disseminated in the future.

Data Analysis Plan

Constant comparison analysis was used for data analysis in this study. This method involves several stages of coding and is recommended for use in focus groups

(Glaser, 1965; Leech & Onwuegbuzie, 2008; Onwuegbuzie, Dickinson, Leech & Zoran, 2009). In constant comparison analysis, data are initially grouped into small units by open coding. The next stage involves axial coding whereby the initial codes are grouped into categories by comparing the data to previous codes (Glaser, 1965). In the final stage, the grouped categories are selectively coded to reveal themes. Glaser (1965) described this as a process of “integrating categories and their properties” (p. 440). Notes taken while facilitating the online focus groups were added to both transcripts as a bracketing measure and to capture the affective domain of participants’ experiences. These procedures are also consistent with the steps of the IPA method (Pietkiewicz & Smith, 2012).

Data analysis was accomplished through review of the data in the hermeneutic circle. The hermeneutic circle involves a process of continual examination of data through several levels of coding to elicit clear interpretation (Pietkiewicz & Smith, 2014; Tuohy, Cooney, Dowling, Murphy & Sexsmith, 2013). As described above, IPA involves open, axial and then thematic coding, a process by which the codes overlap in the hermeneutic circle and therefore require several readings and continual refinement. To conduct this analysis, transcripts were initially reviewed in Microsoft Word format and then organized into a Microsoft Excel spreadsheet where each level of coding was indicated in a separate column and further aligned with the discussion prompts. At this stage, I considered utilizing qualitative data analysis software (QDAS), such an NVivo. Sohn (2017) asserted that there is no conclusive evidence to support the use of QDAS in phenomenological research and describes discourse among experts in the field with respect to the need to bring the method into the future using technology with the opposing belief that technology can challenge the humanistic nature of phenomenology. After extensive analysis of the literature and experimenting with both hand and QDAS analysis himself, Sohn recommended researchers, particularly those who are novice, begin with hand coding and include QDAS if they feel it would facilitate improved data analysis. Bracketing throughout the data analysis phase was also recommended to guide this decision-making process.

The data analysis process concluded following a repeat review of the data, cross-checking in with the analytic memos as a reflexive measure and triangulation using member-checking. Any discrepant cases were planned to be reviewed with the Chairperson and possibly discussed with the participant for clarification. The results of data analysis were then prepared and interpreted in Chapters 4 and 5.

Issues of Trustworthiness

Credibility

Lincoln and Guba (1985) asserted that credibility is one of the most important indicators of trustworthiness. The credibility of this study was established in several ways. I have used seminal and modern examples of interpretive phenomenology to maintain philosophical and methodological alignment. Shenton (2004) suggested researchers engage in prolonged engagement with participants to establish trust and gain a clear understanding of their experiences once situated in their culture. I have worked extensively with eating disorder patients for many years and I believe that disclosing this demonstrated my understanding of participants’ experiences and therefore established trust. Further, I felt that my interpretive lens, informed by a priori, facilitated an accurate understanding of the lived experience of participants receiving community-based eating disorder care in Ontario. I was able to balance my immersion in this culture through several bracketing methods such as analytic memos espousing reflexive commentary, so as to avoid impairment of my professional judgment.

Random sampling, although uncommon in qualitative research, has been recommended as a credibility measure (Shenton, 2004). I used purposeful sampling to determine that interested participants met inclusion criteria and to ensure that those participants prepared to fully engage and share data freely are included (Shenton, 2004). Sampling in this manner ensures that participants who will provide rich, thick data will be selected.

Triangulation and member checking were used for credibility purposes. Triangulation primarily consisted of eliciting data from several sites geographically dispersed across the province and from two separate focus groups to compare and corroborate experiences. My dissertation committee provided valuable peer scrutiny. Through advisement and member checking, my committee members facilitated an important alternative perspective, challenged me to think reflexively, and facilitated refinement of my novice research skills (Shenton, 2004).

Transferability

Transferability is the qualitative measure for external validity and refers to the extent to which findings can be situationally applied (Shenton, 1994). Erlandson, Harris, Skipper and Allen (1993) suggested that this generalizability is never truly possible in qualitative research due to contextual constraint. Lincoln and Guba (1985) recommended that researchers gather as much contextual data as possible for sense-making purposes. I cannot claim that the results of this study are generalizable to the entire population of those with eating disorders, however, the direct focus and aim of this study was to expound the contextual elements of geography, men, nursing, community and this serves as a measure of transferability. Further, the methodology of this study was planned in a manner that maximizes the opportunity to elicit thick, rich and contextual data from a population that can be difficult to access and establish trust with, and with whom discussion of sensitive subject matter may be challenged by cognitive impairment, shame, or the limitations imposed by chronic disease.

Dependability

Dependability refers to the ability to repeat a qualitative study to achieve similar results (Shenton, 1994). Lincoln and Guba (1985) suggested that dependability is often accomplished through measures of credibility. Blended credibility and dependability were accomplished in this study by the clear and detailed articulation of the methodology, the operational detail of how data was gathered and analyzed, and ongoing reflexive analytic memos (Shenton, 1994). Selection of participants from multiple sites increased dependability since findings of this study could more likely be replicated in other areas.

Confirmability

Confirmability is a measure of how accurately the data support the research findings (Patton, 2002). In qualitative research, confirmability is meant to protect the integrity of the participants’ experiences rather than these experiences conforming to the aims of the researcher (Shenton, 2004). To ensure confirmability, I have explicitly reported my assumptions upfront and managed potential bias throughout the research process with triangulation efforts, member checking, and by completing analytic memos. The use of theory as an orientating framework also reduces the researcher's influence.

Ethical Procedures

As chronically and mentally ill young adults represent a vulnerable population, additional measures have been taken to protect participants in this study. First, establishing the need for current and ongoing health care as an inclusion criterion was the best way to ensure that participants were mentally and physically well enough to participate and if participation was triggering to them, they could reach out to their health care provider for support. Next, due to the secretive and shameful feelings individuals with eating disorders often have (Pettersen, Rosenvinge & Ytterhus, 2014), an online discussion forum was used to allow participants to share their experiences without having to do so in the physical presence of a researcher and other participants. This focus group forum also served to address several issues pertaining to participants' physical health. Many individuals with eating disorders tire easily, struggle with cognitive impairment (attention, memory, concentration, decision making, etc.), have activity intolerance and experience anxiety (Hart, Granillo, Jorm, & Paxton, 2011; Herpertz-Dahlmann, Dempfle, Konrad, Klasen & Ravens-Sieberer, 2015; Mattar, Huas, Duclos, Apfel & Godart, 2011). Having access to participate around-the-clock and from anywhere allowed participants to attend required medical appointments/treatment programs without interruption and did not challenge them to travel, leave their comfort zone, or withstand any physical or cognitive demands outside of what they typically would on an average day. Further, interviews and face-to-face focus groups often involve food or drink, interaction with peers/researcher, and/or audio/video recording; all of which may have be distressing to those with eating disorders.

Participant names were maintained as confidential and were only be accessible to the researcher. Participants were strongly advised to use a pseudonym within the online discussion forum in order to protect their identity from their peers. In the consent form, participants were explicitly warned that Internet security cannot ever be infallible and to exercise cautious judgment about what they shared as a result.

To ensure the protection of human subjects in this research, I have strictly followed Walden University's Ethics Guidelines for Clinical Research and I applied for and received Walden's Institutional Review Board (IRB) approval. OCOPED agreed to circulate the recruitment flyer only after IRB approval was received from Walden University and shared with their administrators.

Any potential ethical concerns involving recruitment, data collection, and treatment of data have been circumvented due to careful methodological planning. If participants changed their mind about participating, they could simply refrain from logging into the website. If they changed their mind throughout the course of the study, they could stop participating at any time. Once participants gained access to the website, they had access to ask any questions or address any concerns with the researcher in the focus group forum if they are comfortable discussing the matter in an open environment or by phone if they wished to speak privately. All study information and consents were available in the online forum. Participants were required to complete the consent forms before participating in the focus group. During the two-week period when the focus group is live, the researcher moderated the discussion daily. If any participant indicated any signs of distress, or wrote something that presented a safety concern, the researcher planned to contact them immediately and alert them to two potential eating disorder crisis lines and/or their local 24-hour crisis line. To ensure adequate follow-up care, I also planned to encourage them to contact their care provider.

While every effort was made to ensure protection of the online focus group data, there was no truly infallible security measure on the Internet. Participants were made aware upfront of this potential. The use of a password-protected focus group provided some security of the data, but additional measures were necessary. Data from the focus group was backed up twice weekly during the time that the focus group was live. This data was stored on my password-protected computer at work, located in my locked office. At the completion of the focus group, the transcripts were printed, and the focus group forum was closed. Printed transcripts were stored in a locked file cabinet in my locked office at work, separated from any other documents. The only people who had access to this data were myself and my committee members for purposes of advice, or member checking. Transcripts will be kept separately in this locked file cabinet for a period of five years and at that time, they will be destroyed.

Summary

In Chapter 3, I have provided an overview of the interpretive phenomenological research design, justification for use of asynchronous online focus groups, and measures taken to ensure rigor and trustworthiness. Details have been provided to explain how recruiting occurred through healthcare professionals at each site and how participants remained anonymous. My role as moderator in the asynchronous online focus group forum was addressed along with the nature of the discussion prompts. Alignment between these discussion prompts, and the research question and purpose has been outlined. Finally, measures such as triangulation, member checking, and methodological decision making were discussed in relation to establishing trustworthiness and maintaining ethical research practices.

In Chapter 4, I provide a description of the research settings, demographic information of participants, and data collection procedures. Details about coding and handling of discrepant cases in the data analysis process are reported. This chapter concludes with a discussion of the evidence of trustworthiness in this research study.

Chapter 4: Results

Introduction

The purpose of this interpretative phenomenological study was to explore community-based eating disorder care from the perspectives of young adult patients in Ontario, Canada and establish the context of nursing in community-based care. The primary research question was: what are the lived experiences of young adults receiving eating disorder care in the community? Through asynchronous discussion in online focus groups, participants were asked to share their thoughts and experiences involving past and present eating disorder health care professionals and treatments as well as the meaning and impact of that care.

In this chapter, I detail the setting in which the research took place, the demographics of participants, and methods of data collection and analysis. Results of both the survey to evaluate inclusion criteria and online focus groups are presented. Finally, evidence of trustworthiness is discussed.

Setting

I was approved by Walden University’s IRB (#02-12-10620154) to recruit participants through OCOPED. The recruitment flyer outlined the nature and details of the study and directed interested participants to a Survey Monkey survey intended to confirm eligibility requirements for the research study. Once eligibility requirements were confirmed, participants were invited to join the online focus group that was scheduled for a 2-week period of time and participate asynchronously at their convenience during the prescribed time period. Fliers were planned to circulate to all

OCOPED members via email through the intake coordinator, after OCOPED's Board of Directors reviewed all of Walden University's IRB-approved documents. In the event of poor responses, the IRB approved a total of three reminder emails to be sent to OCOPED members at one-week intervals, followed by snowball sampling as a secondary approach to recruitment.

OCOPED sent flyers to their membership, but no responses were received in the first week via the Survey Monkey survey, and no inquiries were received via my Walden University email address. The intake coordinator re-sent the flyer on three occasions at weekly intervals. Several weeks following the final circulation, I had received no surveys. I did, however, receive an inquiry from an interested individual who did not meet the age criteria for the study. My dissertation committee and I speculated that the timing of this request near high school and college exam time may have negatively impacted participation.

After discussion with my dissertation committee, it was agreed that snowball sampling should begin as a secondary recruitment measure. I sent an email to the interested participant who did not meet the eligibility criteria and that individual agreed to send the flyer to several peers she had met in various treatment programs across the province. Over the next 10 days, 19 surveys were completed. All but one of the survey participants met eligibility criteria and were invited to participate in the online focus groups. Of these 18 individuals, seven participants answered questions in the online focus groups, but only four completed all of the discussion questions. The remaining survey participants were sent two additional emails providing details about how to participate in the online focus groups but none of these individuals returned to participate. The three individuals who started to answer questions in the online focus group but did not finish were also sent an email reminder on two occasions. Additional attempts to snowball sample were made through the seven focus group participants as well as through the primary individual who began the snowball sampling process.

Unfortunately, no further participants were recruited over several months to satisfy the desired 15-20 participants. As a result, I had to submit a Request for Change in Procedures form to the IRB in order the secure a third method of recruitment. Since the individual who successfully began the snowball sampling process did so through social media, I requested permission to post my recruitment flyer on social media sites for several eating disorder-focused community organizations. This request was approved and two of the five nonprofit eating disorder organizations I approached agreed to post the flyers on their social media accounts. No further surveys were completed over a period of several months. My dissertation committee and program coordinator reviewed the data I had collected from the four participants who completed the discussion questions as well as the three who contributed to some of the discussions and collectively determined that the data were strong enough for analysis and saturation was achieved for several of the discussion questions.

Demographics

Demographic data from the online focus group participants is detailed in Table 1. All seven participants were female and between the ages of 18 and 22 with a mean age of 20.14. Participants were split relatively evenly in terms of diagnosis with three individuals having a bulimia nervosa diagnosis and the remaining four having anorexia nervosa. Each participant lived in different town or city. The locations where participants had received care were widely distributed geographically, and as a result most of the more populated areas of Ontario were represented. The number of inpatient hospitalizations varied from zero to more than five and the number of years in outpatient treatment varied from one to more than five. The relationship between treatment duration and number of inpatient hospitalizations was highly variable, with two individuals having 5+ hospitalizations during 5+ years of treatment and others showing a range between four hospitalizations within a single year of treatment and only one hospitalization within 5+ years of treatment.

Table 1

Demographics of Focus Group Participants

#	Gender	Age	Diagnosis	Location	Inpatient Hospitalizations	Outpatient Treatment Years
1	F	21	Bulimia Nervosa	Hamilton	2	2
2	F	20	Anorexia Nervosa	Sarnia	0	1
3	F	20	Anorexia Nervosa	Kitchener	1	2
4	F	21	Bulimia Nervosa	Hawkesbury	1	5+
5	F	19	Bulimia Nervosa	Simcoe	5+	5+
6	F	18	Anorexia Nervosa	Thornhill	5+	5+
7	F	22	Anorexia Nervosa	Sudbury	4	1

Data Collection

Number of Participants

A total of 19 participants completed the eligibility survey, and 18 of these individuals met the criteria for inclusion and were invited to participate. Of these 18 individuals, seven participated in the online focus group discussion. Four of the seven online focus group participants completed all discussion questions. Data were analyzed from all seven participants in the online focus group.

Location, Frequency, and Duration of Data Collection

Data collection occurred only within the online focus group. Each participant had access to the focus group for 2 consecutive weeks, and since the online discussion was asynchronous, they could participate from anywhere and at a time that was convenient for them. The 2-week period of access was extended for those participants who had started but did not complete the discussions. Most participants logged in once and completed all of their discussions at that time, doing so within an average of 50 minutes. Several individuals who started but did not complete the discussion logged in multiple times and three of the four took an average of 64 minutes for each log in.

The period of time during which data were collected in the online focus group was 10 days. However, the data analysis period was significantly lengthier. Due to the challenges I faced during recruitment, the data collection period from IRB approval to the start of data analysis was approximately 9 months in duration.

Recording of Data

Focus group discussions took place in an online platform called Focus Group It. This password-protected online forum collected and stored the data. Additionally, each day during the data collection period, I copied any new discussions from the Focus Group It forum and pasted them into a Word document for security purposes. The Word document was saved onto a password-protected work computer accessible only to me in my locked office and the data was backed up twice weekly while individuals were participating. Once data collection was complete, the final document, including the full transcript, was printed for data analysis purposes. This document was kept in a locked file cabinet in my office. These transcripts were kept confidential aside from sharing it electronically with my dissertation committee members on one occasion to inform the decision about whether saturation had been reached and on a second occasion following data analysis for member checking purposes. Transcripts will remain in my locked file cabinet in my work office for a period of five years and will then be destroyed.

Variations and Unusual Circumstances

Four changes were made to the methodological plans described in Chapter 3. First, and as described previously, modifications were required to complete the recruitment process for this study. Snowball sampling had to be utilized when recruitment measures aimed at eating disorder health care professionals through their professional organization failed to yield any participants. Considering that Reigel, Jaarsma and Stromberg’s (2012) central theoretical concepts of self-care maintenance, self-care monitoring, and self-care management were utilized to keep potential participants safe when planning the methodology, one could surmise that these same concepts may have prevented individuals from participating in the study if they were unwell or unable to do so without compromising their health or wellbeing. Snowball sampling ensured that participants with lived experience with community-based eating disorder care were approached but the anonymity of this method allowed them the chance to participate or decline for any reason with no potential recourse. Further, the individuals who completed the survey but not the focus group and/or those who participated for only a portion of the discussion, may have done so as a measure of self-care. The more frequent logins and longer times to participate for individuals in these demographic groups seem to suggest this possibility.

Second, the challenges presented in the recruitment phase also impacted the intended discussion within the focus groups. This study was planned so that participants could all be active within the focus group at their convenience but within the same two-week period of time. Doing so would have allowed more opportunities for participant-to-participant discussion and had the potential to enrich the dialogue. While there was some participant-to-participant discussion, the gaps of time in recruitment required most participants to engage at different times. Previous researchers have identified the value of inter-participant dialogue in online focus groups (Woodyatt, Finneran & Stephenson, 2016) but have also identified how challenging it is to achieve a fluid conversation between participants when they are not able to have face-to-face discussion (Zwaanswijk & van Dulman, 2014). Conversely, a reduction in social desirability bias is one benefit of having less interaction between participants.

A third variation from the methodology described in Chapter 3 was the intention to recruit male young adults into the study. While one male and one individual identifying their gender as other successfully completed the survey and agreed to participate, neither of these potential participants engaged in the online focus group. During snowball sampling, I did stress the need to share the flyer with both male and female peers but unfortunately, I was unsuccessful in recruiting any male participants.

Finally, I aimed to recruit between 15 and 20 participants but only had seven. While I had previously identified that 15-20 participants were significantly higher than most phenomenological studies require (Mason, 2010), my intention was to acquire more participants in order to achieve a more representative geographical context. The group of seven participants that I did have in the online focus groups met Creswell‘s (2014) criteria for participant numbers in phenomenological studies and was highly representative of the major populated areas of the province.

Data Analysis

Process

The data analysis plan was to use both the constant comparison and the IPA methods for the purposes of trustworthiness and methodological adherence respectively. Both constant comparison analysis and IPA involves grouping data through open, then axial coding to reveal categories and themes. The use of IPA is a measure of credibility since it encouraged me to align the data analysis process closely with both the vulnerable nature of my participants and the theoretical underpinnings of the methodology and study. Further, the addition of constant comparison in the data analysis is a measure of confirmability as it ensured that I was interpreting the similarities and differences between participants accurately. Throughout all three levels of coding, analytic notes were added to the document and coded.

Data were initially copied from the Focus Group It forum into a Word document. In order to use the constant comparison method, the data from each group was kept together and organized into sections based on each of the 11 sub-questions. The analytic notes kept throughout the data collection process were added to the Word document. Pre-coding was completed at that time by highlighting potentially relevant passages in the transcript.

For the first cycle of open coding, the In Vivo coding process was utilized. Saldana (2016) recommended this method of coding for any qualitative study but particularly for beginning qualitative researchers and for studies involving marginalized populations as In Vivo coding, "…honor[s] the participant's voice" (p. 106). There were a total of 319 first level codes.

When I transitioned to axial coding after the first level coding was complete, I elected to utilize In Vivo coding again. My initial attempt at second level coding utilized a traditional axial coding approach, by which researchers aim to remove redundancies, and establish dominant codes (Saldana, 2016). My analytic memos from that coding attempt reveal concern that the participants' voices were being blended from individual voices to a collective voice and that I felt challenged to prioritize one perspective over another. Reflection about the philosophical basis for interpretive phenomenology prompted me to make a second attempt and In Vivo coding was used again to categorize while maintaining autonomy. After several In Vivo coding sessions and reflective periods, the 319 first level codes were grouped into 8 new codes to represent categories.

Several methods were used to complete the data analysis process. Third level coding began with codeweaving; an approach that helps researchers see the most important aspects from each data category (Saldana, 2016). During several rounds of codeweaving, the interrelationships between codes and categories became clear. I then used Saldana's trinity strategy to plot these inter-relationships which led to the identification of three themes. Doing so involved a review of second level codes from a more axial perspective to prioritize the macro, meso, and microlevels of the final codes. A final method utilized was Saldana's touch test, which is used to ensure that the progression from code to concept identification was done at an appropriate level of abstraction.

Evolution of Themes

Through the first two levels of coding described previously, the following categories emerged: released and relapsed, stay on track, let down by system, time out of my life, no rules in the real world, responsible for your own recovery, felt safe there, and let it consume me or live with it. The categories of released and relapsed, let down by the system, no rules in the real world, and responsible for your own recovery, emerged from participants' recall of their transitions to and from treatment as well as day-to-day life while trying to recover. Some examples of first level codes that guided the evolution of these categories include, didn't focus on core issues, needed more structure, work so hard for access, had struggled, still struggle, and not ready for real life. Nearly all of the participants shared that they felt they had to carry the burden of recovery alone. For example, one participant stated, “my eating disorder is my second job,” while another identified herself as the, organizer of her care and that, “[she] didn’t feel like the patient, [she] felt like the caregiver.” In response to the many comments made about systematic barriers to effective treatment, one participant shared, “I think I would have committed to recovery a lot sooner if the resources in my community were better” and shared that with the right supports, she was able to “…let go of the eating disorder bit by bit.”

The categories of stay on track, and felt safe there, emerged from participants’ experiences of securing adequate treatment supports, being successful in treatment and leading toward and/or achieving recovery. These two categories emerged from codes such as, learning to live healthy, people who understood, structured support, build my own team, cross examine my thoughts, compassionate and understanding, and want to see you get better. One participant described her experience of emerging from treatment back into her life in the following way, “I play the role of accepting recovery and jumping in with both feet, working with the health professionals and following what they prescribe, opening up to them and being honest and letting myself heal and focus on recovery.”

Most participants described their eating disorder journey introspectively, leading to the establishment of the final two categories of time out of my life, and let it consume me or live with it. Many described the negative impacts that they experienced with respect to dealing with chronic illness, ongoing system navigation and missed opportunities. Similar codes included, no impact until X years sick, huge time commitment, lost time, used to be my life, and all I thought about. When describing the negative aspect of her journey, one participant poignantly stated, “I had to search for so long… endless … endless.” Conversely, this same participant shared, “my eating disorder means a lot to me because it’s made me the kind caring person I am today,” Several participants referenced their eating disorder experience through a positive lens as well. Related codes included, helped me learn and grow, change for the better, and learn about myself.

Additional codeweaving, Venn diagramming and touch testing facilitated the evolution of these categories into three themes. The three identified themes include (1) living with unmet needs, (2) living with support, and (3) learning to live again. Each theme emerged from two or more categories and several categories are represented in multiple themes. These interrelationships between categories and themes are presented in Figure 1.

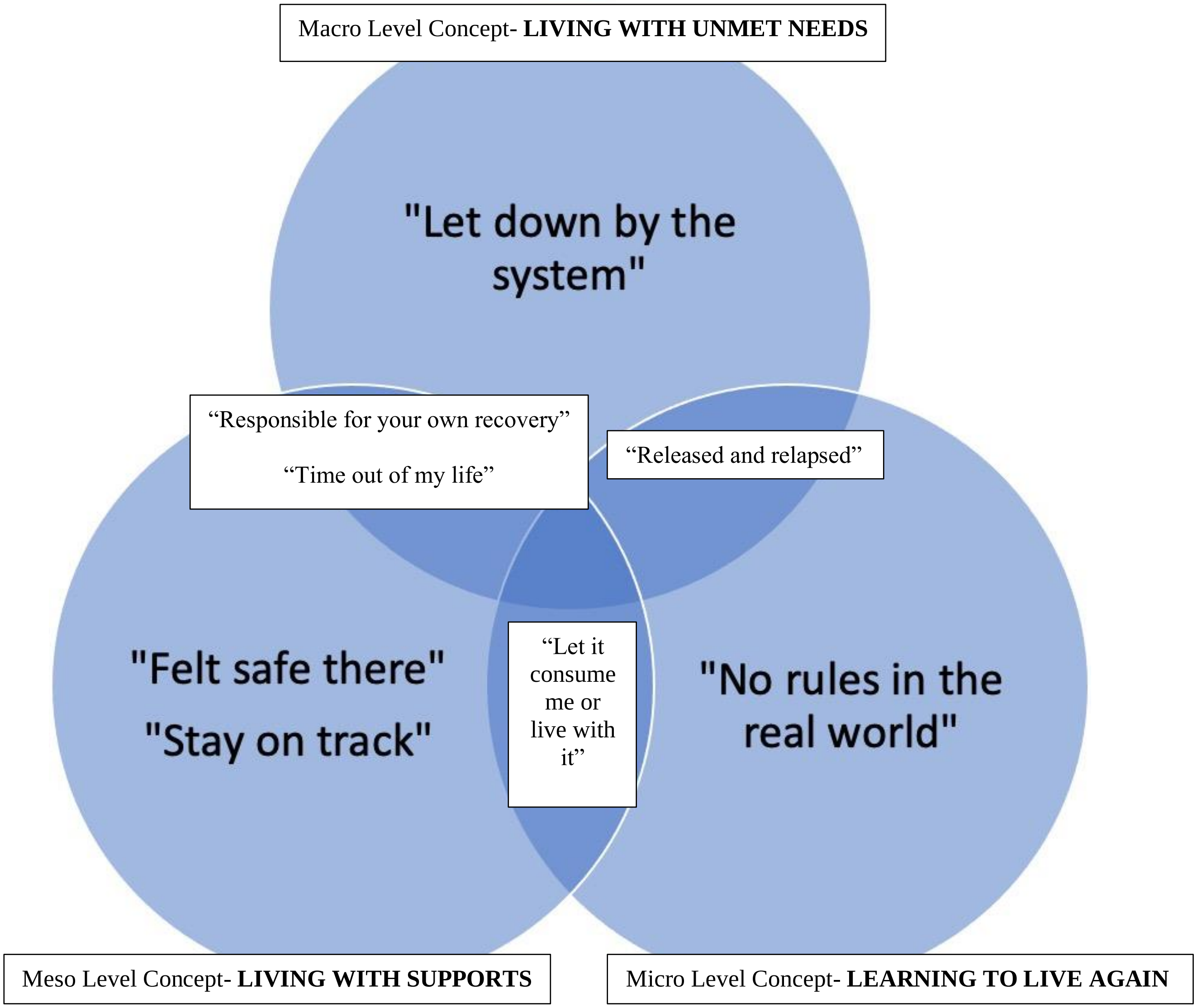

Figure 1. Venn diagram demonstrating Saldana's trinity strategy.

The living with unmet needs theme emerged from the let down by the system category as most of the unmet needs identified related to treatment that was required to support participants in their illness but were unavailable for many reasons. Further contributing to this theme, were the responsible for your own recovery, time out of my life, and released and relapsed categories. Participants commonly described coordinating their own care and how much time, energy and focus this required of them. Similarly, several participants equated some of their treatment failures with this role. One participant described this when she said, “I am almost like my second therapist. I cross examine my thoughts and actions and try to understand why I make mistakes and what I can do to fix it or prevent them next time.”

The living with support theme was derived from the categories of felt safe there, and stay on track. Codes that defined these categories and ultimately, this theme included, safe space, saved my life physically, life back on track, support me, track of recovery, and support and guidance. Other categories that influenced this theme were responsible for your own recovery, time out of my life and let it consume me or live with it, as participants made several positive and negative references to the autonomous role in their care, with and without supports, and the commitment required to do so. To demonstrate the culmination of each category in the theme of living with support, one participant shared:

> They [healthcare professionals] helped me get back on the right path and able to live my life again and have helped me learn and understand more about what I was going through in my eating disorder, what is going on in my brain, what I can

> do in situations where I need to use skills to help manage problems and really just overall I would say I learned a lot about empathy, life, psychology and most of all myself and more about who I am and what I want in life.

The ‘learning to live again’ theme developed after analyzing participants’ experiences transitioning into, between, and out of eating disorder treatment. No rules in the real world, a category where participants shared experiences of learning new coping strategies, managing different levels of supervision and structure, and finding direction for themselves, was the most influential for the development of this theme. Important codes from this category include, successful in isolation?, learning to live healthy, outpatient was a step down, get away with behaviors, treatment had no direction, and unstructured and not very useful. Several of the negative experiences shared in the ‘learning to live again’ theme overlapped with those shared in the released and relapsed category while the majority of positive experiences overlapped with the let it consume me or live with it category. Demonstrating this dichotomous perception, one participant shared, “now my eating disorder means to me that I struggled, I still struggle, but I don’t have that hating piece. I’ve accepted the illness and how I may struggle for the rest of my life but that’s a battle I can’t just give up.”

Management of Discrepant Cases

There were no discrepant cases that needed to be managed in the data set. Experiences of community-based eating disorder care were individually unique but demonstrated strong similarities between participants. Use of the constant comparison method to analyze similarities between two groups allowed me to stay focused on thematic evolution and was a measure of confirmability.

Evidence of Trustworthiness

Credibility

Lincoln and Guba (1985) defined credibility as the truth value of qualitative research. Credibility for this study was demonstrated in several ways. From inception, this study was designed to align the methodology with the orientating theoretical framework and the philosophies of interpretive phenomenology. Based on my professional knowledge of eating disorders and in an attempt to maintain alignment. the methodology was planned to focus on participants' lived experiences in a supportive and non-intimidating online forum.

My a priori knowledge also facilitated credibility. While the two-week duration of the online focus groups alone did not permit me to establish prolonged engagement with the participants, having this time with them in daily facilitation of the forum and participants having knowledge of my extensive experience in eating disorder care, did. Participants were assured that I would understand their perspectives and also that my interpretive lens would facilitate accurate understanding of their experiences.

Additional credibility measures were taken in sampling and data analysis stages. Purposive sampling using the snowball method, helped to ensure participants were prepared to fully engage and share data freely. Since each participant recruited the next, sampling bias on the part of the researcher was controlled (Lopes, Rodrigues, & Sichieri, 1996). Further, participants were required to complete a survey to validate that they met inclusion criteria prior to being invited into the online focus groups. During data analysis, my dissertation committee reviewed my analytic notes and findings as a measure of member checking. The wide geographical dispersion of participants and use of constant comparison methods were measures of triangulation in this study.

Transferability

Transferability is defined as the extent to which findings can be applied situationally (Shenton, 1994). As one of the aims for this study was to establish contextual elements of geography, nursing and community in eating disorder care, the research questions provided opportunity to share experiences in these areas and these contexts were explored in data analysis. While there was not enough data collected to establish a strong of understanding of nursing and community, there were thick, rich data collected to establish basic context surrounding the role geography plays in accessibility, continuity, and perceived efficacy of community-based eating disorder care in Ontario.

Dependability

Shenton (1994) suggested that dependability is best achieved by replicating a study to achieve similar results. By this standard, I was able to see similar data collected in two different groups of unique participants using the constant comparison method. Other measures of dependability include reflexive practices such as member checking, triangulation and analytic memo writing/analysis. The widely representative geographical location of participants also provided stronger dependability for the generalization of findings across the province.

Confirmability

Patton (2002) suggested that confirmability is a reflection of how accurately the data and research findings align. I took several measures to establish confirmability in this study. First, the online chat style forum used to collect data offered a written transcript of the participants' thoughts without the potential to misinterpret or make errors in transcription. To ensure as much meaning could be extracted from the participants' written word, I provided daily moderation of the focus group and asked several follow-up questions when more information was required for sense-making. Although there were open ended research questions to guide the conversation, participants were able to share anything they felt was relevant and important, which, in turn, protects the integrity of the lived experience and allows for the participants to lead the discussion. Finally, I spent a great deal of time establishing my assumptions during the methodological planning phase and I reviewed them several times throughout data collection and analysis as a reflexive measure. Since some degree of bias is inevitable in interpretive phenomenological research (Lopez and Willis, 2004), these confirmability measures were triangulated with member checking of my analytic memos and data analysis findings.

Results

As thematic evolution has already been detailed earlier in this chapter, the results are presented below as they relate to each research question.

Research Question 1- What is Your Experience as a Patient Receiving Eating Disorder Care in the Community?

As participants shared information about their experiences, it became apparent that there was significant variation in the definitions of community-based eating disorder care. One participant described her community-based care by her experiences at home following discharge from multiple inpatient treatment facilities. Another participant described hospital-based eating disorder services that she accessed as an out-patient. Two participants described several non-specialized and non-eating disorder focused outpatient services that they utilized for treatment. Several others described specialized eating disorder services that they received on an out-patient basis. Five of the seven participants described accessing multiple types of treatment, however the remaining two indicated that they too had accesses multiple services in the survey but did not describe them in this forum.

Participants accessed different treatment modalities for a variety of reasons. One participant cited the focus of the treatment program as the reason for transition: “I had gone to treatment as a kid and the program wasn’t very helpful. It was solely focused on mindfulness and the aspect of eating disorders, they didn’t focus on the core of the issue. I was released and relapsed immediately.” She then recounted her second treatment experience that was tailored to her need for trauma-centered care: “I was skeptical at first, but it turned out to be a wonderful experience up to the end. I had exposure to my traumas while in a controlled safe space which allowed me to really get a grasp on my disorder.”

A second participant identified the value of trauma-centered care when she stated, “I find my therapist specializing in emotional trauma helps a lot.” She further explained that eating disorder specialty care is not available in her area so finding a therapist with a trauma specialty was her next best option. Similarly, another participant explained that she too works with a trauma- specialized therapist since eating disorder specialty services are not available in her area and how she had been unable to make the travelling commitment work in the past. Both individuals who report seeing a trauma therapist over an eating disorder-focused therapist identify the value and need for it but also voiced limited progress with respect to eating disorder recovery.

One participant who had utilized a wide variety of modalities and delivery systems for her treatment explained that her improvement was physical in nature and did not facilitate the psycho-behavioral improvements she desired: “The program saved my life physically but I did not experience behavioral improvement.” She further explained that her treatment needs did not always fit with inpatient goals, thereby contributing to fragmented care and inconsistent or less-than desirable outcomes: “Family based treatment was not doable due to significant familial dysfunction. I was hospitalized 3 times on an eating disorder specific unit and 2 times on general psychiatric unit. I never needed weight restoration so my inpatient stays were short and focused only on medical stabilization or crisis intervention.”

Another participant discussed the challenge of having her needs fit into the focus of the program and the impact of incongruency when she stated:

> I used to be in an outpatient program about a year ago. I was not able to finish that program because they said that group therapy ‘wasn’t for me.’ I didn’t have the best experience and I don’t think I would go back to any program. I was really let down by their system.”

This individual has not been affiliated with a specialized eating disorder program since this experience.

For the individuals who seek treatment from their family doctors, their descriptions of the care they receive varied significantly. Some participants described seeing their doctors on an as-needed basis to address signs or symptoms where others describe a level of care similar to what I know to be standard care in eating disorder specialized clinics. For example, one participant shared:

> I saw my family doctor every 1-2 weeks because I was physically unwell but not able to be hospitalized. Currently, I see my family doctor as needed- usually pop in every 6-12 weeks and get orthostatic vital signs and bloodwork which is ordered based on what has been abnormal for me in the past. Get an EKG every now and then if I have chest pain… I’m not on a regular schedule with her its more just “how are you doing” and if my vitals are okay I can schedule a follow up in 6-8 weeks or whenever I have time. If my orthostatic change in heart rate is significant she will have me come in sooner, 3-4 weeks. And based on bloodwork, vitals and a brief physical exam, if she ever felt I was in need of emergency care of IV fluids she would direct me to the ER but that hasn’t happened for a long

> time. She doesn't take my weight unless there is a significant change or sometimes I haven't been weighed in several visits.

Two participants described the importance of having private insurance to supplement the treatment they receive. One worried, "Once I'm finished college I lose my insurance coverage and won't be able to afford [private practice psychology services]. I won't be able to afford to pay out of pocket- so I will have to look elsewhere." Similarly, another participant shared, "I went to treatment in July 1017 until November of the same year and that was amazing however, I would not have been able to have that treatment without my parents insurance and that treatment saved and got my life back on track."

Research Question 2- How Does Community-Based Eating Disorder Care Impact Your Life?

The data that emerged from this discussion was significantly focused on the availability of resources and the geographical context. Five of the seven participants referenced how their location negatively impacted their access to appropriate treatment. Their concerns ranged from overall comments about service delivery on a provincial and federal level to the time required to travel from one's home to out-of-town treatment sources. One participant stated, "There isn't much in Ontario, let alone in Canada. Throughout my struggle when I was struggling, there was no support in or near my area." Another participant shared, "Where I live I don't have many options. I have to travel over an hour to get to any specialist including a dietitian." One participant offered an example of how technology was utilized to bridge the geographical gap for her: "I see my psychologist through distance video sessions online. It is nice because I live rurally and don't have time to travel so the time commitment in minimal." One participant was unable to contribute to the discussion because she said, "In Northern Ontario this does not exist and I am sadly unable to comment on anything of this nature."

Several experiences were shared that demonstrated the impact of inequitable access. One participant stated, "I think I would have committed to recovery a lot sooner if the resources in my community were better. I tried to recover multiple times before but didn't have the proper resources to help me physically as well as understand mentally what was going on with me," and another shared, "If I had received more trauma related therapy while conducting eating disorder therapy, I believe recovery would've been a sooner option." A third participant lamented about lost time due to lacking resources when she stated, "the point is, community-based care didn't impact my life until I was already x number of years sick."

Another impact discussed by participants was fiscal in nature. A participant explained a situation where she was financially impacted but also elucidated consideration for cost at a systems level: "I was hospitalized for the first time due to the lack of resources. It was cheaper to stay than to travel back and forth."

The remainder of impact-related discussions surrounding health equity were of a personal nature. A participant described how her treatment experience has improved since moving to a city from a rural location: "Now being in a bigger city the awareness is spreading, there is more support groups for mental health and eating disorders." Two participants shared dissatisfaction with their individual needs not being met by the programs available to them when they stated, “It [my current community-based eating disorder treatment program] provides me with some support but not as much as I currently need,” and, “I didn’t have a strong relationship with the clinician who was treating me, so when it came to talking about it, it was generally uncomfortable.” Conversely, another participant shared how her treatment in the community positively impacted her:

> It basically helped save my life for a year I didn’t know if I would be in life anymore and my family was desperate to find some sort of help. Finding the outpatient clinic was a God save and they helped me start on the track of recovery and connected me to another agency. Now I am back on track in life and found happiness again. The community help was key in this.

Research Question 3- How is the Care You Receive in the Community Different Than What You Have Received as an In-Patient?

Structure was the most prominent consideration that emerged from the discussion of inpatient and outpatient treatment comparison. Most participants who had experienced both delivery systems indicated that in-patient programs were more structured. One participant asserted, “In patient is treated a lot more seriously,” and another shared, “I had structured support, regular group therapy, and wasn’t able to engage in any binging/purging/restricting behaviors. I felt safe there…” Another participant shared the following account of how the inpatient treatment structure facilitated her recovery:

> Inpatient care has helped me immensely... I find in the community it’s really difficult to find the right fit for a team and in [inpatient care] I lived there and it

> was very intensive. There were nurses on the unit 24/7 and we had a schedule for the day. It helped as it forced me to do things I couldn't bring myself to do or did know how to do in my sick state.

By comparison, participants suggested that the less structured treatment protocols in outpatient programs presented challenges for them. One participant said, "it [inpatient treatment] is completely different than going to a therapist or family doctor who might only know a little bit on the subject and I felt like I can get away with behaviors as there are no 'rules' in the real world." A second participant referenced the increased autonomy required for outpatient care when she said, "Where as outpatient was almost a step down [from inpatient care] and is more for if you are a bit better at being responsible for your recovery." This participant also provided insight into the realities of day-to-day out-patient treatment:

> …you go to your outpatient appointment and are there meeting with the professionals for an hour or two and then they send you home with your package of stuff to do and you are left to think of meals yourself for the most part and to prepare them and regulate yourself into doing the treatment and recovery steps.

One participant shared an account of what made her in-patient experience positive, thereby elucidating what treatment characteristics are desired by patients: "I was skeptical at first but it turned out to be a wonderful experience up to the end. The staff was remarkable, understanding and the girls were very welcoming."

When discussing the negative aspects of outpatient treatment, there were several references to the lack of specialized eating disorder treatment when accessing community resources. One participant mused, “Seeing someone in private practice I sometimes feel as if the treatment has no direction. I worry about the accountability of my therapist and whether they are giving me evidence-based treatment.” Another shared concerns about the preparedness of her health care providers to treat her eating disorder: “My family doctor basically didn’t know what to do with me. More awareness could help.” A third participant shared, “What I did enjoy about being in a specific eating disorder program is that I was surrounded by people who understood the struggle and the staff were specifically trained for eating disorders. I was held accountable and wasn’t allowed to engage in eating disorder behaviors while in the program.” After seeing community-based professionals with no specialized training, a final participant concluded, “community-based care has been very unstructured and not very useful.”

One participant eluded that treatment is most successful when it is tailored to an individual’s present needs and that traditional outcomes associated with eating disorder treatment evaluation may not be the only value to patients in receipt of outpatient care:

> …I was at outpatient on and off for a few months and it was hard to keep myself on track in the state I was in as even physically I wasn’t doing very well and my body was malnourished which made it hard to function as my brain was taking the fall as well, however the outpatient helped me start on the track and did help a bit. I didn’t feel as alone or helpless anymore once I found it. I would have appointments a couple times a week and then I decided I didn’t want to go for a bit and then I realized I should try out [inpatient treatment] so I went back and told the nurse and she was able to set it up for me. It was also hard to accept that I

> might need to go to inpatient or gain weight or follow the advice of the team in outpatient so at some points I just didn’t even want to hear it however that’s normal when you are just starting trying to recover it is so hard to have that acceptance.

Similarly, another participant indicated that it is challenging for a patient to secure community-based providers independently in the outpatient setting that functions with the team dynamic that is already established in in-patient care: “Inpatient care has helped me immensely in the times that I’ve been an inpatient. I find in the community its really difficult to find the right fit for a team and I’ve had people on my team give up on me.” The benefit of having different health care professionals meet different needs was addressed by another participant:

> It took a lot to have anyone penetrate the walls of the eating disorder. Some days it seemed like no one could get into where my thoughts were, until I had maybe say a different member of my team offer me a new skill sourced from a different method to get me through difficult thoughts, moments or even meals.

A final participant referenced her thoughts on outpatient treatment teams by saying:

> I have had to build my own team and figure out how to make that work for me. And still, there isn’t even a dietician who specializes in eating disorders. Inpatient care is the only thing that has brought me multi-disciplinary care for my eating disorder which is the only effective mechanism to recovery that I have experienced.

Research Question 4- Describe the Role You Play in Your Care

The need to play an autonomous role in one’s care was addressed by each participant. Some examples of autonomous action include organization, scheduling, researching, self-soothing and self-assessment. One participant shared, “I look at all the information I was given in the sessions, I did my research on my illness to better understand it, I comforted myself when Ed [eating disorder] was vividly prominent and no one would help.” Another participant said, “For me it’s hard because it almost feels like everything revolves around setting up appointments and being the one coordinating makes it feel like if I wasn’t then I wouldn’t be getting any form of treatment or support.” After sharing a very similar account of her responsibilities in her care, another participant said, “I don’t feel like the patient, I feel like the caregiver even though it is for myself.” A final participant discussed the conflicting autonomous role with the lack of supervision inherent in a community-based setting:

> … I have complete responsibility for everything with little accountability. No one tracks my weight besides, me, and I self-report any changes. I could easily say I’m doing fine because there are no measures like weight checks, bloodwork, or self-monitoring sheets to support whether I am describing an accurate picture of how my time has been between sessions. I have to try to advocate for myself…

The other reference made in this discussion pertained to engagement with treatment. Three participants discussed how they had to make the conscious decision about treatment buy-in but the ways in which they did so seemed to be correlated to their stage of recovery. One participant whose accounts demonstrate that she is currently struggling with her illness described engagement simply, yet poignantly as, “My role is to decide whether or not I schedule appointments and go to said appointments.” Through her treatment journey and nearing toward recovery, another participant explained: “Opening up to them and being honest and letting myself heal and focus on recovery, let people help me and let go of the eating disorder bit by bit.” Finally, a third participant, who was one year into recovery, described her role this way: “I play the role of accepting recovery and jumping in with both feet, working with the health professionals and following their recommendations and what they prescribe.”

Research Question 5- What Does Your Eating Disorder Mean to You?

Although each participant’s account of meaning in this discussion was uniquely individual, there were several similarities noted. Nearly all participants addressed meaning derived from coping, control and/or comfort. One participant said:

> My eating disorder is a way to cope with past trauma and current situations of my life. When I engage in behaviors, it gives me a sense of control and comfort. For me it started as a way to manage my weight and morphed into a security blanket of sorts.

Very similarly, another shared:

> My eating disorder has been the way I have coped with abuse and trauma for almost 8 years. At first, it was a way to lose weight but now, it is largely driven by habit and a way to attempt to regulate my emotions.

Another participant shared a third account that was very similar to the first two:

> For me my eating disorder is something that I use to cope with things that have happened and continue to happen in my life. It gives me a sense of control and security that I otherwise don't really have (or at least not in the same way). It numbs the pain and gives a sense of comfort in some ways.

In addition to the facets of coping, control and comfort that constructed meaning for participants, several also discussed an evolution in the development of such meaning. One shared:

> At first my eating disorder felt like a sign of weakness and a part of me I couldn't control. It was something I hated in myself and was disgusted. This I believe fed into my ideas, plunging me deeper into the illness. Now my eating disorder means to me that I struggled, I still struggle, but I don't have that hating piece.

Two participants discussed how their attributed meaning changed from negative to positive over time when they stated: "It was a struggle and rough point in my life and was something I went through like how someone would have an illness or go through a hard time. It helped me learn and grow and change for the better" as well as:

> My eating disorder used to be my life, it was all I thought about, I would constantly be comparing myself to others and judging others. Now I am more compassionate, it's still all I think about but I think about it in a different way, I try to flip my thoughts to positive things or things I am proud of. My eating disorder means a lot to me because it's made me the kind caring person I am today.

Research Question 6- Describe Your Experiences in the Health Care System Since the Onset of Your Eating Disorder

In this discussion, participants elected to address a variety of highly individualized foci. Nearly all of the experiences shared were negative, thereby demonstrating a collective frustration with the health care system. Two system-directed frustrations that were addressed by several participants included validation of illness and issues of accessibility.

With respect to illness validation, one participant said, “in my local ER, reactions to me have generally been surprisingly positive with all physical symptoms taken seriously and evaluated in a timely manner.” Such a statement seems to denote that either this individual has experienced less attentive care in the past or possibly that those with eating disorders feel they have to advocate for quality healthcare. Another participant explained her similar perception: “honestly I haven’t had such good experiences with the health care system. A lot of times medical professionals don’t take me seriously even when I’m considered medically unstable…. unless you’re severely underweight or on death’s door, you’re not sick enough.” A final participant shared an experience whereby she felt her illness was only being addressed in the physical context:

> Nobody understands. Everyone pushes mental health to the side and says it must be something physical that can be fixed. They don’t try to understand the mental part of it because it’s too confusing and complicated. I felt like a lab rat to the point I almost stopped helping myself because I felt so discouraged.

Challenges in accessing treatment were also discussed. Reference was made to the length of waitlists for treatment, the availability of specialized eating disorder services, as well as service inequity based on insurance status. One participant shared her perspective on the time and effort required to secure appropriate treatment when she said:

> My experience was that I found the help and resources I needed but it took a long time just to find resources as I had to search for so long. Endless endless googling just trying to find what could help me as I did not know anything about [treatment services] or anything that could help me because I didn't really know it was coming for me…The care was good once I got it. I think it's just definitely room for improvement.

Research Question 7- Do You Feel That the Place You Live Impacts Your Healthcare?

All participants indicated that location was an important consideration in meeting healthcare needs. Participants who lived rurally, and those who live in cities and towns far away from metropolitan areas discussed the challenges of seeking out, securing and travelling for eating disorder care.

Another consideration shared by one of these rurally-located participants was that of stigma: "I think being in a small town there's so much stigma behind mental health still so there's not as many reliable options for people like myself."

One participant who had moved from a rural location to a metropolitan area described the differences in services in the two geographical locations:

> Yes, because it is a smaller town up north. The population isn't sufficient enough for a large medical specialist in eating disorders when there's thousands of cases in Toronto daily. However, the help is still needed to those who struggle EVERYWHERE.

A second participant, living in a large metropolitan area identified that accessibility remained a problem for her, not due to the lacking services, but due to the competition of a greater population to access them. She highlighted the unfortunate realities of waiting for care when she shared:

> I live in Toronto, and I think it depends. On one hand the amount of units and places to get inpatient help is limited and waitlists can be long- 1 year + long. And by the time your name comes up on the list it's not always soon enough. I've lost friends because they were dying but the people doing the intake and putting them on lists didn't take them seriously enough and they couldn't hold on. I've come close to losing my life to this illness because waitlists and distances interfere.

Research Question 8- Describe Your Experiences With Health Care Professionals Who Have Been Involved in Your Care

In this discussion, participants shared highly individual experiences with a large number of professionals in many different health care disciplines. Two concepts that emerged in several participant accounts were consistency and a lack of knowledge about eating disorder care.

Two participants described receiving inadequate care from well-intentioned yet eating disorder-ignorant health care professionals. One participant described a situation where she sought care from both a practitioner of alternative and Western medicine but did not receive the holistic care she was anticipating:

> I went to a natural doctor. He told me I had candida and needed to start this diet to cure it. Then my actual doctor just thought I had a stomach ulcer or something never asked about the rest of my health just sent me to get every test done in the book…

Another participant shared, "I have had really great experiences with the eating disorder professionals however with my general family doctor I think he wasn't fully sure what to do for me when I came to him with my problem." By comparison, she also shared the experience she had once she has secured a team that was equipped to deliver evidence-informed eating disorder treatment:

> Eventually when I found the professionals who specialized in eating disorders like the three women I worked with in the outpatient clinic, a nurse, dietician and social worker and the professionals at the eating disorder inpatient unit. They were all very experienced and knew what they were doing when it came to what I was dealing with.

Consistency in care was also described by a second participant who shared:

> My physician has been really supportive and amazing throughout everything; she's a really big support for me, and the same goes for my dietician. I've been with my physician since 2014 and my dietician since 2015; they're the only part of my treatment team that haven't changed and I'm very grateful to have both of them caring for me. As for social workers and psychologists I've seen a lot of

> different ones throughout my care which has honestly been quite frustrating. It's hard to always be starting fresh and feel like you're always being passed round and given up on.

Research Question 9- Have Your Experiences With Nurses Differed From Your Experiences With Other Health Care Professionals?

All participants but one discussed their experiences with nurses who were specialized in eating disorder care. Alternatively, one participant explained that she had only had contact with nurses at the start of her eating disorder journey. The nurses in her account were not informed about eating disorders and as a result, her needs for evidence-based care were left unmet:

> The only experience I've had is with the nurses at my doctor's office. I explained what was going on with me and they insisted it was something physical and I needed to get tested for ulcers and stuff like that instead of recognizing it was mental.

The positive encounters with eating disorder specialized nurses shared by the other participants referenced their therapeutic skills, knowledge, and attention. One participant shared:

> Nurses experienced in work with eating disorders tended to be more compassionate and better able to provide appropriate care. They generally were able to provide quality treatment while being sensitive to the needs of patients. They also were more aware of eating disorder behaviors (like weight

> manipulation for example) and consequently able to deliver more appropriate care (blind weights, weights in a gown, voiding before weights, etc.).

This same participant also provided insight into one way eating disorder nurses may demonstrate advocacy and facilitate communication when she said, “nurses also serve as an approachable liaison between doctor and patient.” A second participant commented that, “nurses knew the rules and were very good with supporting the patients, there was always a nurse to talk to or to get help with anything else. They were very helpful.” A final participant further shared:

> I’ve found many times that the nurses are really supportive and good listeners. Most of them genuinely care about you and your wellbeing and actually want to support you. They take the time with you and want to see you get better.

Research Question 10- What Do You Think the Ideal Role is for Nurses to Play in Community-Based Eating Disorder Care?

Participation in this discussion was limited to four participants. Two participants addressed the need for specialized education for nurses working in the eating disorder field. One explained:

> I think if nurses are dealing with eating disorder care they need to have special training. It is so easy to trigger someone or say the wrong things so to prevent any further hurt in the hospital that would be my suggestion. I know so many people that have been hospitalized but left more discouraged cause of a comment they got from a nurse.

Another participant provided an example of the specialized training that nurses should have and her vision of the impact such an investment may have for those seeking care:

> Nurses in community-based care could serve as an affordable way for the government to provide more basic medical monitoring for eating disorder patients. I think nurses taking orthostatic vitals, weights and history is well within their scope of practice and could help treatment teams serve more patients in the community.

The other two participants addressed the therapeutic skills required by nurses to effectively care for eating disorder patients. One commented on the value of taking a holistic approach to eating disorder patients whose illness is comprised of both physical and psychosocial components:

> I think it is important for there to be nurses taking part in eating disorder care as it is a mix of mental illness and an illness that has physical effects. It’s important for there to be a nurse who is monitoring health when it comes to physical stuff like weight, hormones, vitamins, etc. and other physical health concerns. As well the nurses at my inpatient treatment center helped with medication, drawing blood, and all around care and even support outside of that like talking and checking in with the patients on emotions and other things.

Research Question 11- How Have Your Experiences with Community-Based Eating Disorder Care Shaped You?

The most discussed concept addressed for this question related to personal development as a result of individual experiences in one’s eating disorder treatment journey. One participant shared that her experiences have inspired her to give back: “They’ve shaped me into who I am today. I applied to social service work so I can go through school (slowly cause I need to work on my grades) and help people like myself for an affordable price.” Another participant described the lessons she learned from treatment, her caregivers and her peers:

> They helped me get back on the right path and able to live my life again and have helped me learn and understand more about what I was going through in my eating disorder, what is going on in my brain, what I can do in situations where I need to use skills to help manage problems and really just overall I would say I learned a lot about empathy, life, psychology, and most of all myself and more about who I am and what I want in life. It also taught me a lot about acceptance and I have a whole new view on healthcare and life experiences especially from all the people I met who also had eating disorders.

The third participant expressed mixed feelings about the gains and losses she experienced as a result of eating disorder treatment:

> I’ve had a lot of ups and downs in my experiences, but they’ve also contributed to my present day life. I have met some amazing nurses, doctors, dieticians, therapists, etc. that have really impacted me throughout all of this. But I’m also still struggling immensely, and the system is failing me. My current therapist is giving up on me just like everyone else, and nobody knows what to do with me. I’m at a loss, a pothole in this road. Maybe it will change, but maybe it won’t; I

> mean with the way things are right now I don’t think it could get any better and that’s a terrifying thought.

A final participant shared about the specific losses she had endured as a result of her treatment and the impacts those losses had on her development and connections to others:

> My experiences in community-based care have impacted my ability to attend school full-time. When I had to travel for outpatient care I missed a lot of school and had to attend a modified alternative education program. This delayed by ability to graduate on time with my same age peers. I lost touch with most of my friends from high school and have had to dedicate a lot of time to establish myself and new relationships in the community.

Summary

In Chapter 4, I described the setting in which this study took place, participant demographics, as well as data collection and data analysis measures. Results were presented for each research question. Measures of trustworthiness were also detailed.

The central research question was: What are the lived experiences of young adults receiving eating disorder care in the community? The results revealed valuable insights into the experiences of treatment for the participants in this study. Participants shared highly individualized and unique definitions of community-based treatment and referenced multiple types of treatment delivery systems and professionals who cared the them within those systems. Satisfaction with care delivered in community-based programs varied from highly satisfied to deeply dissatisfied and may relate to an individual’s stage of recovery. The meaning of eating disorders to participants ranged from negative to positive and seemed to evolve during one’s recovery journey but was consistently constructed from the need for coping, control and comfort.

Participants clearly identified what they felt was both desirable and necessary to provide effective community-based care. There was a great emphasis on the need for specialized education and training for those working in eating disorders and many participants shared negative experiences of being cared for by well-intentioned but ill-prepared health care professionals. Participants also identified the value of individualized, holistic, timely, accessible, multidisciplinary, equitable and team-cohesive eating disorder care. Engagement was identified as important in treatment and was found to be positively influenced by program structure and negatively influenced by the burdens inherent in the autonomous care coordination role. Accessibility to adequate treatment was influenced by insurance coverage, the length of waitlists, and an individual’s effort to advocate for their care. Participants described a challenging self-advocacy process of lost time and energy whereby they needed to seek out, secure and often travel for care.

When addressing care providers, participants defined the characteristics and skills sets that are necessary to effectively meet the needs of patients with eating disorders. Individuals shared that they wanted to be heard and taken seriously by the professionals they encounter in their pursuit of treatment. Therapeutic skills such as listening, specialized eating disorder knowledge and attentive caring were discussed specifically as important skills for nurses to ensure their efficacy in the eating disorder field.

In Chapter 5, I discuss the findings, limitations of the study, recommendations for further research, and social change implications.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was to explore the experiences of young adults undergoing outpatient eating disorder treatment in Ontario, Canada using a phenomenological methodology. The contexts of geography, nursing, and community-based eating disorder care were also examined with the intention of explaining how the current delivery of eating disorder care impacts patients. The primary research question was: “What are the lived experiences of young adults receiving eating disorder care in the community? Research sub-questions addressed past and present healthcare experiences and interactions with health care professionals as well as the impact and meaning of the care received.

Online discussion forums allowed participants to share their stories and yielded highly unique and individualized descriptions of experiences. Definitions of community-based treatment varied widely as did the types of professionals who provided care within such programs. Patient satisfaction with care seemed to be influenced by the degree to which individuals were affected by their eating disorders and the degree to which their healthcare professionals were trained in the eating disorder specialty. Similarly, the meaning attached to eating disorders ranged from highly negative to deeply positive and again, was aligned with individual progress toward recovery. The purpose of eating disorders, however, was consistently described as a means to achieve coping, control or comfort.

Other key findings involve participant descriptions of community-based care requirements to meet patient needs. Specialized education and experiences of health care professionals were addressed in terms of strength of care received but also in the context of negative experiences whereby participants acknowledged that their providers were doing the best they could with what they knew about eating disorders. Participants constructed ideal eating disorder care as individualized, holistic, accessible, equitable, and timely and emphasized the value of a multidisciplinary, evidence-informed and cohesive team approach. With respect to ideal nursing care, participants identified the need to be heard and taken seriously. Many participants shared that the structure of inpatient programs facilitated their engagement and lack of structure in community-based treatment required them to assume coordination of their own care, a role many found arduous, resulting in lost time, the need to travel for care, and expenditure of self-advocacy energy they did not have.

Interpretation of the Findings

Williams and Reid (2012) as well as Tierney (2008) discussed the dichotomous relationship individuals have with their eating disorders and this was certainly evident in the data for this study. Feelings of love and hate directed at one’s illness were quite common and appeared to culminate in a sense of appreciation for what was learned from eating disorders when recovery was achieved. This finding is interesting given that hope for the future and gaining self-acceptance were found in previous studies to be indicative of treatment commitment and motivation (Fogarty & Ramjan, 2016). Further, an eventual positive outlook on one’s disease course was found among participants with both anorexia and bulimia nervosa, and this may have important implications for bulimic treatment since self-efficacy was identified by Lindgren, Enmark, Bohman and Ludstrom (2014) as a critical precursor to symptom interruption and recovery.

Results of this study strongly re-iterated the bio-psychosocial, functional, economic and quality of life challenges that are associated with eating disorder affliction (DeJong et al., 2013; Hart, Granillo, Jorm & Paxton, 2011). Sheridan and McArdle (2016) cited community-based eating disorder care as a means to improve quality of life while Newton, Bosanac, Mancuso and Castle (2013) credited outpatient treatment with improving psychopathology and functionality. An unexpected finding contrary to the literature, was that participants had more positive experiences in in-patient treatment than they did in community-based care. Participants associated their negative outpatient experiences to the lax structure, standardized delivery, inconsistent team dynamics and lack of specialized knowledge and skill among providers.

All participants in this study identified barriers to eating disorder treatment with the most prominent barriers being negative past treatment experiences and service restrictions. Stigma was much less concerning to young adults than it was to adults in previous studies (Innes, Clough, & Casey, 2017), possibly indicating a generational comfort in discussing mental illness. Thompson and Park (2016) also found that past experiences influenced treatment access and satisfaction, however the degree to which past experiences are influential appear to be more profound in young adults. In this study, past experiences often guided decision making about treatment long after experiences had occurred, which led to challenges in terms of therapeutic alliances with care providers and made young adults hesitant to seek care, thereby perpetuating their illness. This finding is in sharp contrast to research findings of decreased symptomology in young adulthood (Dolan, Evans, & Lacey, 1992; Heatherton, Mahamedi, Striepe, Field, & Keel, 1997; Keel, Baxter, Heatherton & Joiner, 2007; Keel, Fulkerson & Leon, 1997) but may be explained by individual experiences or variances in treatment programs.

Barriers to health access were a consistent finding a ultimately informed dissatisfaction with the health care system. Participants living rurally or outside of metropolitan areas where Ontario eating disorder programs are typically located were the most negatively impacted, citing costs, cumbersome travel, limited access, and loss of quality and treatment time as negative outcomes. Even participants living in large cities or in closer proximity to treatment programs described access issues due to waitlists and overcrowding. These findings are consistent with those of adult eating disorder programs (Innes, Clough, & Casey, 2017) and therefore introduce a basic understanding of how barriers affect young adults seeking community-based treatment and elucidate more understanding of the geographical context absent in the literature.

Individual descriptions of community-based treatment programs were highly variable, thereby challenging the establishment of a community context for eating disorders. Some participants described community-based treatment in a manner consistent with primary care, others referenced outpatient therapy services and finally, others described multidisciplinary team programs whereby they received specialized care. Similar inconsistencies have been found previously in eating disorder programs within the Canadian healthcare system (Norris et al., 2013) as well as in the utilization of the few evidence-informed practice guidelines in eating disorder treatment (Von Ranson, Wallace, & Stevenson, 2012; Winston, Paul & Juanola-Borrat, 2012).

The age of young adults transitioning between pediatric and adult standards of care could further complicate this matter. Existing research suggests that cost reduction (Rosling, Ros & Swenne, 2016; Sheridan & McArdle, 2016), de-institutionalization philosophies (Wiseman, Sunday, Klapper, Harris & Halmi, 2000) and young adult patient preference (Sheridan & McArdle, 2016) supported the transition from inpatient to community-based treatment for eating disorders, however, with such inconsistent definitions and program delivery systems, quality improvement and efficacious outcomes will be difficult to achieve. As a result, the vision for community-based eating disorder care established by the OCOPED is not being consistently realized.

Few participants had contact with nurses in their community-based treatment programs and most drew from their experiences with nurses on inpatient units to participate in this discussion. Experiences with nurses who were specially trained in eating disorder care were positive, while experiences with nonspecialized nurses were not as helpful from an eating disorder treatment perspective but were well-received when nurses were holistic and therapeutic in terms of their approach. While there is no literature that directly addresses the nursing role in community-based treatment, these findings align with a strong body of research emphasizing the value of therapeutics in eating disorder health care from both the patient (Fogarty & Ramjan, 2016; Sheridan & McArdle, 2016; Zugai, Ryan, Malson, Clarke, Anderson & Kohn, 2006; Stein-Parbury & Roche, 2012) and nurse (Snell, Crowe, & Jordan, 2009; Wright, 2015) perspectives.

When dealing with other health care professionals, participants described issues with consistency, lack of specialized knowledge and disconnection; all of which support the existing research in adolescent care. Similarly, Dimitropoulos et al. (2015) found that partnered care, with a greater focus on emotional rather than physical treatment, was preferred by participants while transitioning from adolescent to adult care. Participants in this study made similar suggestions for improvement to young adult care and specifically focused on trauma-informed emotional treatment. An additional new recommendation for treatment was assistance with care coordination due to the intensely burdensome nature of this role.

It is important to examine research findings within the context of the theoretical framework (Creswell, 2014). Riegel, Jaarsma, and Stromberg's (2012) middle range theory of self-care in chronic illness was used as an orientating framework for this study. The major concepts of self-care management, self-care maintenance, and self-care monitoring were evident in participant descriptions of coordinating their own treatment. Several of the factors that influence self-care management, maintenance and monitoring within this theory were evident in the data, including experience, motivation, confidence, support from others, and access to care. Limited access to specialized care due to travel, proximity, and financial restraint resulted in participants providing a great deal of self-care. Their ability to advocate for the care they needed was often compromised by restrictions imposed by their mental and physical illness as well as lacking motivation. Individuals described spending time and energy more on care coordination than they were able to spend providing self-care and advocating for their healthcare needs. Despite communicating frustration about the onerous nature of self-care, participants overwhelmingly communicated that they valued listening and attentive caring from their care providers, which may suggest a desire to engage in self-care. Confidence in one's ability to provide self-care seemed to develop as recovery did. The fact that most participants reported increased satisfaction with their treatment were either recovered or close to recovery may imply that wellness, time and/or experience may increase self-care confidence, an important determinant of self-care (Luciani et al., 2020).

Riegel et al. (2019) described several challenges to self-care that are pertinent to the findings of this study. These include the influence of habit formation on behavior change, resilience in the face of stressful life events that interfere with self-care, the influence of culture on self-care behavioral choices, the difficulty performing self-care with multiple chronic conditions, self-care in persons with severe mental illness, and the influence of others on self-care. While the literature supports a connection between all of these challenges and eating disorders, those that resonated strongly within this study involve resilience, physical co-morbidities including mental illness, the influence of health care professionals and culture in terms of societal pressures that drive eating disorders and complicate their treatment.

Limitations of the Study

There are several important limitations to acknowledge in this study. The participant group, although strongly representative for age, diagnosis, location and various treatment histories, was very small and therefore findings are limited in terms of transferability. Additionally, the highly variable definitions of community-based treatment by participants further challenge collective impressions to be drawn from the data. As a result of the smaller than desired number of participants, and inconsistent participation from some in the discussions, saturation was not achieved for several individual research questions, particularly those relating to the community and nursing contexts. However, once coding and codeweaving was employed during the data analysis process, thematic saturation was achieved.

Another challenge to generalizability is that fact that no male or transgender participants were successfully recruited. Despite my intention to elicit the experiences of the under-researched male and transgender groups, snowball sampling produced a group of female-only participants and therefore results are not generalizable beyond women. Snowball sampling also opens a study to the risk of selection bias, although this risk was mitigated by the process being exclusively respondent-driven and conducted within an anonymous platform.

Further limitations in this study include data collection challenges and researcher bias. Inconsistent and/or incomplete participation in some of the discussions, coupled with lack of peer-to-peer interaction, may have resulted in the loss of the data richness that is typical of focus groups. Also, meaning derived exclusively from written communication inherently loses some intention, emotion or context. Finally, several measures were taken to bracket my a priori knowledge; however, some inherent bias on my part must be acknowledged.

Recommendations

Findings from this study revealed several potential directions for additional research. First, a follow up study would be helpful to expand upon and substantiate findings further. Using a similar methodology that more purposely recruits participants beyond the female gender and from more similarly structured, nurse-led community-based treatment programs in Ontario would elicit more understanding of the male patient, nursing and community contexts that are lacking in the current body of evidence. Next, the contextual element of community-based eating disorder care that I was unable to elucidate within this research project, should be studied further. Due to widely variable program delivery across the province and inconsistent definitions of community-based treatment in patients and within the scholarly literature, the community context is an important priority to establish. Next, it would be valuable to explore the inpatient experiences of individuals with eating disorders in Ontario since participants in this study indicated a much higher level of satisfaction with this delivery model than they did in community-based programs. It may also be of value to comparatively study satisfaction quantitatively and quantitatively in both inpatient and outpatient treatment programs with the intention to use that understanding for patient-centered quality assurance purposes. Third, I would recommend collaborative inquiry where eating disorder researchers and clinicians from the pediatric, adolescent and adult fields endeavor to explore patient experiences longitudinally to provide a focused assessment of changing developmental needs throughout treatment. Doing so would be feasible given the typically long duration of illness and prudent since outcomes are poorer for those whose eating disorders persist into adulthood (Ackard, Richter, Egan & Cronemeyer, 2014; Herpertz-Dahlmann, Dempfle, Konrad, Klasen & Ravens-Sieberer, 2015). Finally, participants in this study tended to be more satisfied with their community-based care when they were near or at the recovery stage and this would be interesting to study quantitatively to ascertain whether a correlation exists as this has significant implications for practice.

Implications

The results of this study have several implications. Implications for positive social change is addressed first, followed by those that impact nursing practice. Finally, the implications for further inquiry and theoretical development are discussed.

Positive Social Change Implications

Positive social change implications for individuals, organizations, and society may be derived from this study's findings. From the individual perspective, awareness raised by this study is beneficial. Participants who shared their stories were given a platform with which to enlighten others who cannot understand their disease process first hand; an opportunity that is not common given the stigma and secrecy surrounding eating disorders. Further, this experience allowed participants to share the intimate details of their eating disorder journeys in a safe space and have their voices heard. When the results are disseminated, eating disorders patients, as well as their families and friends who support them, can be confident that health care professionals, organizations, researchers and policy makers will be made aware of their stories in hopes of influencing improvements to eating disorder care infrastructure.

From an organizational perspective, there is potential for this study to inform further research inquiry and practice review. This research generated initial evidence to justify the unique needs of young adults in eating disorder care and could be the impetus for further evidence that is not directly addressed in existing treatment program protocols nor in the scholarly literature. Data collected in this study could also be used to draw together further multi-disciplinary clinicians, researchers and possibly even patients, in patient-focused care reform efforts. Both positive and negative treatment experiences shared by participants can be used to construct program evaluation and quality improvement measures.

At the systems level, this research may have implications for attitudinal, fiscal and policy change. Giving a voice to marginalized groups through research contributes to larger efforts to challenge societal attitudes and stigma surrounding eating disorders. Since eating disorder care is primarily delivered in community-based programs across Ontario currently, this study provides some evidence of program efficacy from the patient perspective, presents important criteria for consideration in evaluation, and has implications for funding. Applying the facets of inpatient eating disorder care that participants valued to community-based treatment has the potential to inform long-term efforts to decrease attrition, improve efficacy and reduce costly hospitalizations.

Methodological, Theoretical and Empirical Implications

Scholarly contributions of this research include methodological, theoretical and empirical implications. The use of online focus groups and the middle range theory of self-care in chronic illness in this research study has provided an opportunity to apply this data collection method and orientating framework to eating disorder inquiry and adds to our understanding of their practicality. As discussed previously, this study initiated inquiry into a large gap in the existing literature about the young adult experience and role of the nurse in community-based eating disorder care in Ontario, Canada. Additional research can continue to add to further understanding of these contexts. While the male patient experience, nursing and community contexts were not fully realized in this study, explicit identification of this gap may inspire future research interest and endeavor.

Recommendations for Practice

From a practice perspective, I would recommend that clinicians heed the feedback provided by the participants of this study. It should be standard practice to ask patients about past treatment experiences, not only to ensure appropriate continuation of care, but also to develop understanding and empathy for their journey and to provide insight into their needs. Understanding patient perspectives of their care can also inform advocacy efforts to support patients directly and to strengthen the health care system to provide quality care. Findings from this study stressed the significant impact of nurse-patient relationships and as such, nurses should refine and value their therapeutic skills. Lastly, piloting nurses in case management roles has the potential to reduce the burden of self-coordination that participants in this study found so difficult.

Conclusion

Despite community-based care being established as the primary eating disorder treatment delivery model in Ontario, there is still much that is unknown about this phenomenon. This interpretative phenomenological study addressed a significant gap in the literature involving the patient experience within community-based eating disorder care in Ontario, Canada. Asynchronous online focus group discussion revealed highly individualized experiences with outpatient treatment, ranging from successful treatment that was perceived as curative and positively influential to those that did not meet biopsychosocial needs and led to feelings of disappointment with self, care providers and the system. Although there was much variance in definitions of community-based treatment, patient needs of outpatient care were clearly identified and involved a shift to accessible, individualized, holistic, multidisciplinary care provided by engaged and therapeutic professionals.

References

Ackard, D. M., Richter, S., Egan, A., & Cronemeyer, C. (2014). Poor outcome and death among youth, young adults, and midlife adults with eating disorders: An investigation of risk factors by age at assessment. *International Journal of Eating Disorders, 47*, 825-835. doi:10.1002/eat.22346

American Psychological Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Anorexia Nervosa & Related Eating Disorders (2016*). Statistics: How many people have eating disorders?* Retrieved from https://www.anred.com/stats.html

Aspen, V., Weisman, H., Vannucci, A., Nafiz, N., Gredysa, D., Kass, A. E.,… Taylor, C. B. (2014). Psychiatric co-morbidity in women presenting across the continuum of disordered eating. *Eating Behaviors, 15*(4), 686-693. doi:10.1016/j.eatbeh.2014.08.023

Ausili, D., Barbaranelli, C., Rossi, E., Rebora, P., Fibrizi, D., Coghi, C…. Riegel, B. (2017). Development and psychometric testing of a theory-based tool to measure self-care in diabetes patients: The Self-Care of Diabetes Inventory. *BMC Endocrine Disorders, 17*(66). doi:10.1186/s12902-017-0218-y

Baiden, P., den Dunnen, W., & Stewart, S. L. (2013). Discharge of adolescents with mental health problems against medical advice: Findings from adult mental health inpatient facilities across Ontario, Canada. *Psychiatry Research, 2010*, 1161-1167. doi:10.1016/j.pschres.2013.09.024.

Ballard, J. & Crane, D. R. (2015). Eating disorders treatment patterns by age. *Eating Disorders, 23*, 262-274. doi:10.1080/10640266.2014.981427

Benner, P. (Ed.). (1994). *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness.* Thousand Oaks, CA: SAGE Publishing

Bezance, J., & Holliday, J. (2014). Mothers' experiences of home treatment for adolescents with anorexia nervosa: An interpretive phenomenological analysis. *Eating Disorder, 22,* 386-404. doi:10.1080/10640266.2014.925760

Boydell, N., Fergie, G., McDaid, L., & Hilton, S. (2014). Avoiding pitfalls and realizing opportunities: Reflecting on issues of sampling and recruitment for online focus groups. *International Journal of Qualitative Methods, 13*, 206-223. doi:10.1177/1609406914001300109

Breiner, S. (2003). An evidence-based eating disorder program. *Journal of Pediatric Nursing, 18*(1), 75-80. doi:10.1053/jpdn.2003.14

Broussard, B. B. (2004). Women's experiences of bulimia nervosa. *Journal of Advanced Nursing, 49*(1), 43-50. doi:10.111.j.1365-2648.2004.03262.x

Brown, T. A. & Keel, P. K. (2012). The impact of relationships on the association between sexual orientation and disordered eating in men. *International Journal of Eating Disorders, 45*, 792-799. doi:10.1002/eat.v45.6

Bruggen, E. & Willems, P. (2008). A critical comparison of offline focus groups, online focus groups and e-Delphi. *International Journal of Market Research, 51*(3), 363-379. doi:10.2501/S1470785309200608

Burton, M. (2014). Understanding eating disorders in young people. *Practice Nursing, 25*(12), 606-610. doi:10.12968/pnur.2014.25.12.606

Cachelin, F. M. & Striegel-Moore, R. H. (2006). Help-seeking and barriers to treatment in a community sample of Mexican American and European American women with eating disorders. *International Journal of eating Disorders*, *39*(2), 154-161. doi:10.1002/eat.20213

Canadian Agency for Drugs and Technologies in Health (2011). *Admission and treatment of patients with anorexia: Guidelines and recommendations*. Retrieved from https://www.cadth.ca/media/pdf/htis/oct-2011/RB0432-000%20Eating%20Disorder%20Guidelines.pdf

Canadian Pediatric Society (2003). Age limits and adolescents. *Pediatric and Child Health*, *8*(9), 577. doi:10.1093/pch/8.9.577

Canty-Mitchell, J. (2001). Life change events, hope, and self-care agency in inner-city adolescents. *Journal of Child and Adolescent Psychiatric Nursing*, *14*(1), 18-31. doi:10.111/j.1744-6171-2001.tb00285.x

Carter, N., Webb, C., Findlay, S., Grant, C., & Van Blyderveen, S. (2012). The integration of a specialized eating disorders nurse on a general inpatient pediatric unit. *Journal of Pediatric Nursing*, *27*, 549-556. doi:10.1016/j.pedn.2011.06.014

Casanave, C. P. & Li, Y. (2015). Novices' struggles with conceptual and theoretical framing in writing dissertations and papers for publication. *Open Access Publications, 3*, 104-119. doi:10.3390/publications3020104

Clinton, D., Almlof, L., Lindstrom, S., Manneberg, M., & Vestin, L. (2014). Drop-in access to specialist services for eating disorders: A qualitative study of patient experiences. *Eating Disorders, 22*, 279-291. doi:10.1080/10640266.2014.912553

Cohn, L., Murray, S. B., Walen, A., & Woolbridge, T. (2016). Including the excluded: Males and gender minorities in eating disorder prevention. *Eating Disorders, 24*(1), 114-120. doi:10.1080/106400266.2015.1118958

Conroy, S. A. (2003). A pathway for interpretive phenomenology. *International Journal of Qualitative Methods, 2*(3). doi:10.1177/160940690300200304

Cook-Cottone, C. P. (2015). Incorporating positive body image into the treatment of eating disorders: A model for attunement and mindful self-care. *Body Image, 14,* 158-167. doi:10.1016/j.bodyim.2015.03.004

Cook-Cottone, C. P. (2016). Embodied self-regulation and mindful self-care in the prevention of eating disorders. *Eating Disorders, 24*(1), 98-105. doi:10.1080/10640266.2015.1118954

Coombs, A. (2011). Case study: Treating eating disorders in the community. British Journal of School Nursing, 6(6), 284- 288. doi:10.12968/bjsn.2011.6.6.284

Cooper, Z., Bailey-Straebler, S., Morgan, K. E., O’Connor, M. E., Caddy, C.,… Fairburn, C. G. (2017). Using the Internet to train therapists: Randomized comparison of two scalable methods. Journal of Medical Internet Research, 19(1), 355. doi:10.2196/jmir.8336

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, CA: SAGE Publishing.

Dalle Grave, R. (2011). Eating disorders: Progress and challenges. *European Journal of Internal Medicine, 22*, 153-160. doi:10.1016/j.ejim.2010.12.010

DeJong, H., Oldershaw, A., Sternheim, L., Samarawickrema, N., Kenyon, M. D., Broadbent, H.,… & Schmidt, U. (2013). Quality of life in anorexia nervosa, bulimia nervosa and eating disorder not-otherwise-specified. *Journal of Eating Disorders*, *1*(43). doi:10.1186/2050-2974-1-43

de Oliveira, C., Macdonald, E. M., Green, D., Colton, P., Olmstead, M., Bondy, S., & Kurdyak, P. (2016). Cost evaluation of our-of-country care for patients with eating disorders in Ontario: A population-based study. *CMAJ Open*, *4*(4), 661-667. doi:10.9778/cmajo.20160057

Dervin, B. (1983). *An overview of sense-making: Concepts, methods and results to-date*. Paper presented at the annual meeting of the International Communications Association. Dallas, TX. Retrieved from http://faculty.washington.edu/wpratt/MEBI598/Methods/An%20Overview%20of%20Sense-Making%20Research%201983a.htm

DeVos, J. A., LaMarre, A., Radstaak, M., Bijkerk, C. A., Bohlmeijer, E. T., & Westerhof, G. J. (2017). Identifying fundamental criteria for eating disorder recovery: A systematic review and qualitative meta-analysis. *Journal of Eating Disorders, 5*(34). doi:10.1186/s40337-017-0164-0

Dimitropoulos, G., Toulany, A., Herschman, J., Kovacs, A., Steinegger, C., Bardsley, J.,…Kaufman, M. (2015). A qualitative study on the experiences of young adults with eating disorder transferring from pediatric to adult care. *Eating Disorders, 23*, 144-162. doi:10.1080/10640266.2014.976106

Dolan, B., Evans, C., & Lacey, J. H. (1992). The natural history of disordered eating behavior and attitudes in adult women. *International Journal of Eating Disorders, 12*, 241-248. doi:10.1002/1098-108X(199211)12:3<241::AID-EAT2260120303>3.0.CO;2-6

Dooley-Hash, S., Lipson, S. K., Walton, M. A., & Cunningham, R. M. (2013). Increased emergency department use by adolescents and young adults with eating disorders. *International Journal of Eating Disorders, 46*, 308-315. doi:10.1002/eat.22070

Eating Disorders Coalition (2014). *Facts about eating disorders: What the research shows*. Retrieved from http://eatingdisorderscoalition.org.s208556.gridserver.com/couch/uploads/file/Eating%20Disorders%20Fact%20Sheet.pdf

Eddy, K. M. (2013). Patient morality as a predictor of burnout among clinicians specializing in eating disorders. *Psychotherapy, 50*(4), 568-569. doi:10.1037/a0030574

Erlandson, D. A., Harris, E. L., Skipper, B. L. & Allen, S. D. (1993). *Doing naturalistic inquiry: A guide to methods.* Thousand Oaks, CA: SAGE Publishing

Fichter, M. M., & Quadflieg, N. (2016). Mortality in eating disorders: Results of a large prospective clinical longitudinal study. *International Journal of Eating Disorders, 49*, 391-401. doi:10.1002/eat.22501

Findlay, S., Pinzon, J., Taddeo, D., & Katzman, D. K. (2010). Family-based treatment of children and adolescents with anorexia nervosa: Guidelines for the community physician. *Pediatric Child Health, 15*(1), 31-35. doi:10.1093/pch.15.1.31

Flood, A. Understanding phenomenology. *Nurse Researcher, 17*(2), 7- 15. doi:10.7748/nr2010.01.17.2.7.c7457

Fogarty, S. & Ramjan, L. (2016). Factors impacting treatment and recovery in Anorexia Nervosa: qualitative findings from an online questionnaire. *Journal of Eating Disorders, 4*(18). doi:10.1186//s40337-016-0107-1

Fox, F. E., Rumsey, N., & Morris, M. (2007). “Ur skin is the thing that everyone sees and you can’t change it!”: Exploring the appearance-related concerns of young people with psoriasis. *Developmental Neurorehabilitation, 10*(2), 133-141. doi:10.1080/13638490701217594

Gadamer (1975). *Truth and method*. London, UK: Sheed & Ward.

Glaser, B. G. (1965). The constant comparative method of qualitative analysis. Social Problems, 12(4), 436-445. Retrieved from http://scholar.google.ca/scholar_url?url=https://www.researchgate.net/profile/Jacob_Stein/post/Data_analysis_method_in_qualitative_study/attachment/5a8a90e54cde266d588c1010/AS%253A595671249850368%25401519030501430/download/the%2Bconstant%2Bcomparative%2Bmethod%2BGlaser%2B1995.pdf&hl=en&sa=X&scisig=AAGBfm3yQDLiB-cdVZ6_t0wrGHRbzYE9ww&nossl=1&oi=scholarr

Government of Canada (2006). The human face of mental health and mental illness in Canada 2006. Retrieved from http://www.phac-aspc.gc.ca/publicat/human-humain06/pdf/human_face_e.pdf

Gowers, S. & Bryant-Waugh, R. (2004). Management of child and adolescent eating disorders: The current evidence base and future directions. *Journal of Child Psychology and Psychiatry, 45*(1), 63-83. doi:10.1046/j.0021-9630.2003.00309.x

Griffiths, S., Murray, S. B., Dunn, M., & Blashill, A. J. (2017). Anabolic steroid use among gay and bisexual men living in Australia and New Zealand; Associations with demographics, body dissatisfaction, eating disorder psychopathology and quality of life. *Drug and Alcohol Dependence, 181*(1), 170-176. doi:10.1016/j.drugalcdep.2017.10.003

Guillaume, S., Gorwood, P., Jollant, F., Van den Eynde, F., Courtet P., & Richard-Devanoty, S. (2015). Impaired decision-making in symptomatic anorexia and bulimia nervosa patients: a meta-analysis. *Psychological Medicine, 45*, 3377-3391. doi:10.1017/S003329171500152X

Hannon, J., Eunson, L, & Munro, C. (2017). The patient experience of illness, treatment, and change, during intensive community treatment for severe anorexia nervosa. *Eating Disorders, 25*(4), 279-296. doi:10.1080/10640266.2017.1318626

Harmsen, I. A., Mollema, L., Ruiter, A. A., Paulussen, T. G., deMelker, H. E., & Kok, G. (2013). Why parents refuse childhood vaccination: A qualitative study using online focus groups. *BMC Public Health, 13*, 1183. doi:10.1186/1471-2458-13-1183

Hart, L. M., Granillo, M. T., Jorm, A. F., & Paxton, S. J. (2011). Unmet need for treatment in the eating disorders: A systematic review of eating disorder specific treatment seeking among community cases. *Clinical Psychology Review, 31*, 727-735. doi:10.1016/j.cpr.2011.03.004

Harrison, A., Tchanturia, K., Naumann, U., & Treasure, J. (2012). Social emotional functioning and cognitive styles in eating disorders. *British Journal of Clinical Psychology, 51*, 261-279. doi:10.1111/j.2044-8260.2011.02026.x

Hautula, L., Helenius, J., Vaananwn, A., Liuksila, P., Raiha, H., Valimaki, M…. & Saarijarvi, S. (2008). Adolescents with fluctuating symptoms of eating disorders: A 1-year retrospective study. *Journal of Advanced Nursing, 62*(6), 674-680. doi:10.1111/j.1365-2648.2008.04697.x

Heatherton, T. F., Mahamedi, F., Striepe, M., Field, A. E., & Keel, P. K. (1997). A 10-year longitudinal study of body weight, dieting, and eating disorder. *Journal of Abnormal Psychology, 106*, 11-125. doi:10.1037/0021-843X.106.1.117

Heidegger, M. (1962). *Being and time*. Oxford, UK: Blackwell. Retrieved from http://pdf-objects.com/files/Heidegger-Martin-Being-and-Time-trans.-Macquarrie-Robinson-Blackwell-1962.pdf

Hemingway, A. (2011). Life-world-led care: Is it relevant for well-being and the fifth wave of public health action? *International Journal of Qualitative Studies on Health and Well-Being, 6*(4), 1-7.

Herpertz-Dahlamm, B., Dempfle, A., Konrad, K. & Ravens-Sieberer, U. (2015). Eating disorder symptoms do not just disappear: The implications of adolescent eating-disordered behavior for body weight and mental health in young adulthood. *European Child and Adolescent Psychiatry, 24*, 675-684. doi:10.1007/s00787-014-0610-3

Hickey, G. & Hardyman, R. (2000). Using questionnaires to ask nurses about working in the community: Problems with the definition. *Health and Social Care in the Community, 8*(1), 70-78. doi:10.1046/j.1365-2524-2000.00201.x

Hoek, H. W. (2007). Incidence, prevalence, and mortality of anorexia and other eating disorders. Current Opinions in Psychiatry, 19(4), 389-394. doi:10.1097/01.yco.0000228759.95237.78

Hudson, J. I., Hiripi, E., Pope, H. G., & Kessler, R. C. (2007). The prevalence and correlated of eating disorders in the National Comorbidity survey replication. Biological Psychiatry, 61(3), 348-358. doi:10.1016/j.biopsych.2006.03.040

Innes, N. T., Clough, B.A., & Casey, L. M. (2016). Assessing treatment barriers in eating disorders: A systematic review. *Eating Disorders: The Journal of Treatment & Prevention, 25*(1). doi:10.1080/10640266.2016.1207455

Kalnes, K. (2013). *Influence of Social Media Use on Adolescent Females' Perceptions of Their Body Image* (Doctoral Dissertation). Retrieved from https://search-proquest-com.ezp.waldenulibrary.org/pqdtlocal1005747/advanced?accountid=14872

Kass, A. E., Wang, A. Z., Kolko, R. P., Holland, J. C., Altman, M. Trockel, M….Wilfley, D. E. (2015). Identification as overweight by medical professional: Relation to eating disorder diagnosis and risk. *Eating Behaviors, 17,* 62-68. doi:10.1016/j.eatbeh.2014.12.013

Katzman, D. K. (2005). Medical complications in adolescents with anorexia nervosa: A review of the literature. *International Journal of Eating Disorders, 37,* 552-559. doi:10.1002/eat.20118

Keel, P. K., Fulkerson, J. A., & Leon, G. R. (1997). Disordered eating precursors in pre- and early adolescent girls and boys. *Journal of Youth and Adolescence, 26,* 203-216. doi:10.1023/A:1024504615742

Keel, P. K., Baxter, M. G., Heatherton, T. F., & Joiner, T. E. (2007). A 20-year longitudinal study of body weight, dieting, and eating disorder symptoms. *Journal of Abnormal Psychology, 116,* 422-432. doi:10.1037/0021-843X.116.2.422

Kind, S. J. & de Sales Turner (2000). Caring for adolescent females with anorexia nervosa: Registered nurses' perspective. *Journal of Advanced Nursing, 32*(1), 1390147. Retrieved from the CINAHL Plus with Full Text database.

King, S. J. & Turner, D. (2000). Caring for adolescent females with anorexia nervosa: Registered nurses' perspective. *Journal of Advanced Nursing, 32*(1), 139-147. doi:10.1046/j.1365-2648.2000.01451.x

Lather P. (1991). Deconstructing/deconstructive inquiry: The politics of knowing and being known. *Educational Theory, 41*(2), 153-173. doi:10.1111/j.1741-5446.1991.00153.x

Le, L. K., Hay, P., & Mihalopoulos, C. (2018). A systematic review of cost-effectiveness studies of prevention and treatment for eating disorders. *Australian & New Zealand Journal of Psychiatry, 52*(4), 328-338. doi:10.1177/0004867417739690

Leech, S. & Onwuegbuzie, A. J. (2008). Qualitative data analysis: A compendium of techniques for school psychology research and beyond. *School Psychology Quarterly, 23*, 587-604. doi:10.1037/1045-3830.23.4.587

Liechty, J. M., & Lee, M. J. (2013). Longitudinal predictors of dieting and disordered eating among young adults in the U.S. *International Journal of Eating Disorders, 46*, 790-800. doi:10.1002/eat.22174

Lightfoot, K. (2016). *Public Health Leaders' Perceptions of and Attitudes Concerning Eating Disorders* (Doctoral Dissertation). Retrieved from https://search-proquest-com.ezp.waldenulibrary.org/pqdtlocal1005747/advanced?accountid=14872

Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: SAGE Publishing.

Lindgren, B. M., Enmark, A., Bohman, A., & Lundstrom, M. (2014). A qualitative study of young women's experiences of recovery from Bulimia Nervosa. *Journal of Advanced Nursing, 71*(4), 860-869. doi:10.1111/jan.12554.

Linville, D., Benton, A., O'Neil, M., & Sturn, K. (2010). Medical providers' screening, training and intervention practiced for eating disorders. *Eating Disorders, 18*, 110-131. doi:10.1080/10640260903585532

Lopes, C. S., Rodriguez, L. C., & Sichieri, R. (1996). The lack of selection bias in a snowball sampled case-control study on drug abuse. *International Journal of Epidemiology, 25*(6), 1267- 1270. doi:10.1093/ije/25.6.1267

Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research*, *14*, 726. doi:10.1177/1049732304263638.

Loth, K. A., MacLehose, R., Bucchianeri, M., Crow, S., & Neumark-Sztainer, D. (2014). Predictors of dieting and disordered eating behaviors from adolescence to young adulthood. *Journal of Adolescent Health, 55*(5), 705-712. doi:10.1016/j.adohealth.2014.04.016

Luciani, M., Rossi, E., Rebora, P., Stawnychy, M., Ausili, D., & Riegel, B. (2020). Clinical and socio-demographic determinants of self-care maintenance, monitoring and management in US adults with Type 2 Diabetes Mellitus. *Clinical Nursing Research,, 1054773820916987.* doi:10.1177/1054773820916987

MacNeil, B. A., Nadkarni, P., Leduc, S., & Leung, P. C. (2016). Hurry up and "weight": Innovative inter-professional outpatient care for a service user with severe anorexia nervosa awaiting admission to (specialized elective) inpatient care in Canada. *Canadian Journal of Community Mental Health, 35*(3). doi:10.7870/cjcmh-2016-040

Mansfield, J. L. & Wade, T. (1999). Assessing the relevance of the hopelessness theory of depression to women with disordered eating. *Journal of Eating Disorders, 28*(1), 113-119. doi:10.1002/(SICI)1098-108X(200007)28:1<113::AID-EAT14>3.0.CO;2-K

Martorell-Poveda, M. A., Martinez-Hernaez, A., Careller-Maicas, N., & Correa-Urquiza, M. (2015). Self-care strategies for emotional distress among young adults in Catalonia: A qualitative study. *International Journal of Mental Health Systems, 9*(9). doi:10.1186/s13033-015-0001-2

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Qualitative Social Research, 11*(3). Retrieved from the CINAHL Plus with Full Text database.

Mattar, L., Haus, C., Duclos, J., Apfel, A., & Godart, N. (2011). Relationship between malnutrition and depression or anxiety in Anorexia Nervosa: A critical review of the literature. *Journal of Affective Disorders*, *132*, 311-318. doi:10.1016/j.jad.2010.09.014

McCormack, J., Watson, H. J., Harris, C., Potts, J., & Forbes, D. (2013). A hub and spokes approach to building community capacity for eating disorders in rural Western Australia. *Australian Journal of Rural Health, 21*, 8-12. doi:10.111/ajr.12007

McEwen, M. & Wills, E. M. (2014). *Theoretical basis for nursing* (4th ed.). Philadelphia, PA: Wolters Kluwer Health.

McVey, G. L., Davis, R., J=Kaplan, A. S., Katzman, D. K., Punhas, L., Geist, L…. & Forsyth, G. (2005). A community-based training program for eating disorders and its contribution to a provincial network of specialized services. *International Journal of Eating Disorders, 37*, 35-40. doi:10.1002/eat.20114

Mehler, P. S. & Andersen, A. F. (2010). *Eating disorders: A guide to medical care and complications* (2nd ed.). Baltimore, MD: The Johns Hopkins University Press.

Mehler, P. S. (2011). Medical complications of bulimia nervosa and their treatments. *International Journal of Eating Disorders, 44*, 95-104. doi:10.1002/eat.20825

Mitchison, D., Dawson, L., Hand, L., & Hay, P. (2016). Quality of life as a vulnerability and recovery factor in eating disorders: A community-based study. *BMC Psychiatry, 16*, 328. doi:10.1186/s12888-016-1033-0

Mond, J. M., Mitchison, D., & Hay, P. (2014). Eating disordered behavior in men: Prevalence, impairment in quality of life, and implications for prevention and health promotion. In L. Cohn & R. Lemberg (Eds.), *Current findings on males with eating disorders* (pp. 195-215). Philadelphia, PA: Routledge.

Murdoch, J. (2016). Process evaluation for complete interventions in health services research: Analysing context, text trajectories and disruptions. *BMC Health Services Research, 16*; 407. doi:10.1186/s12913-016-1651-8

National Association of Anorexia Nervosa and Associated Disorders (ANAD) (2015). *Eating disorder statistics*. Retrieved from http://www.anad.org/get-information/about-eating-disorders/eating-disorders-statistics/

National Eating Disorder Information Centre (2014). *Statistics.* Retrieved from http://nedic.ca/know-facts/statistics

National Initiative for Eating Disorders (2017). *Canadian research on eating disorders*. Retrieved from http://nedic.ca/sites/default/files//Canadian%20Research%20on%20Eating%20Disorders%20-%20Formatted.pdf

National Institute for Health and Clinical Excellence (2004). *Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders*. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/23346610

Nelson, J. (2016). Using conceptual depth criteria: addressing the challenge of reaching saturation in qualitative research. *Qualitative Research, 17*(5), 554-570. doi:10.11771/1468794116679873

Newell, C. (2004). Nursing and eating disorders. *European Eating Disorders Review, 12*, 1-3. doi:10.1002/erv.564

Newton, J., Bosanac, P., Mancuso, S., & Castle, D. (2013). Bridging the gap: Does a specialist eating disorder service, aimed at developing a continuum of community care, make a difference? *Australasian Psychiatry, 21*(4), 365-370. doi:10.1117/1039856213486303

Noordenbos, G., Oldenhave, A., Muschter, J., & Terpstra, N. (2002). Characteristics and treatment of patients with chronic eating disorders. *Eating Disorders, 10*, 15-29. doi:1064-0266/02

Norris, M., Strike, M., Pinhas, L., Gomez, R., Elliott, A., Fergusin, P., & Gusella, J. (2013). The Canadian eating disorder program survey- Exploring intensive treatment programs for youth with eating disorders. *Journal of the Canadian Academy for Adolescent Psychiatry, 22*(4), 310-316. Retrieved from the MEDLINE Plus database.

Oakley Browne, M. A., Wells, J. E., & McGee, M. A. (2006). Twelve-month and lifetime health service use in Te Rau Hinengaro: The New Zealand Mental Health Survey. *Australian and New Zealand Journal of Psychiatry, 40*(10), 855-864. doi:10.1080/j.1440-1614.2006.07.16.4.20.c7158

Ontario Community Outreach Program for Eating Disorders (n.d.). *Ministry of Health Funded Eating Disorder Programs in Ontario*. Retrieved from http://www.ocoped.ca/Portals/0/documents/Contact_document_080115.pdf

Ontario Community Outreach Program for Eating Disorders (2017). *Nurse practitioner led-care centres.* Retrieved from http://www.ocoped.ca/Services.aspx\

Onwuegbuzie, A. J., Dickinson, W. B., Leech, N. L., & Zoran, A. G. (2009). A qualitative framework for collecting and analyzing data in focus group research. *International Journal of Qualitative Methods, 8*(3), 1-21. doi:10.1177/160940690900800301

O'Reilly, M. & Parker, N. (2012). 'Unsatisfactory saturation': A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research, 13*(2). Retrieved from the CINAHL Plus with Full Text database.

Orem, D. E. (2004). Reflections of nursing practice science: The nature, the structure and the foundation of nursing sciences. *Dependent-Care & Nursing, 12*(3), 4-11. Retrieved from the CINAHL Plus with Full Text database.

Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice* (4th ed.). Thousand Oaks, CA: SAGE Publishing.

Peterson, C. B., Becker, C. B., Treasure, J., Shafran, R., & Bryant-Waugh, R. (2016). The three-legged stool of evidence-based practice in eating disorder treatment: Research, clinical, and patient perspectives. *BMC Medicine, 14*(69). doi:10.1186/s12916-016-0615-5

Pettersen, G., Rosenvinge, J. H., & Ytterhus, B. (2008). The “double life” of bulimia: Patients’ experiences in daily life interactions. *Eating Disorders, 16*, 204-211. doi:10.1080/10640260802016696

Pietkiewicz, I. & Smith, J. A. (2012). A practical guide the using interpretative phenomenological analysis in qualitative research psychology. Psychological Journal, 18(2), 361-369. Retrieved from the PsycINFO database.

Public Health Agency of Canada (2003). *Canadian Pediatric surveillance program 2003 results*. Retrieved from http://www/phac-aspc.gc.c/publicat/cpsp-pcsp03/page6-eng.php

Ramjan, L. M. (2004). Nurses and the ‘therapeutic relationship’: Caring for adolescents with anorexia nervosa. *Journal of Advanced Nursing, 45*(5), 495-503. doi:10.1046/j.1365-2648.2003.02932.x

Raveneau, G., Feinstein, R., Rosen, L. M., & Fisher, M. (2014). Attitudes and knowledge levels of nurses and residents caring for adolescents with an eating disorder. *International Journal of Adolescent Medicine and Health, 26*(1), 131-136. doi:10.1515/ijamh-2013-0015

Ravitch, S. M. & Carl, N. M. (2016). *Qualitative research: Bridging the conceptual, theoretical, and methodological.* Thousand Oaks, CA: SAGE Publishing.

Regan, P., Cahelin, F. M., & Minnick, A. M. (2017). Initial treatment seeking from a professional health care provider for eating disorders: A review and synthesis of potential barriers to and facilitator of ‘first contact.’ *International Journal of Eating Disorders, 50*, 190-209. doi:10.1002/eat.22683

Reisner, S. L., Randazoo, R. K., Hughto, J. M. W., Peitzmeier, S., DuBois, L. Z., Pardee, D. J….Potter, J. (2017). Sensitive health topics with underserved patient populations: Methodological considerations for online focus group discussions. *Qualitative Health Research, 1*(16). doi:10.1177/1049732317705355

Riegel, B., Jaarsma, T., & Stromberg, A. (2012). A middle-range theory of self-care of chronic illness. *Advances in Nursing Science, 35*(3), 194-204. doi:10.1097/ANS.0b013e318261b1ba

Riegel, B., Dunbar, S. B., Fitzsimmons, D., Freedland, K. E., Christopher, S. L., Middleton, S….. & Jaarsma, T. (2019). Self-care research: Where are we now? Where are we going? *International Journal of Nursing Studies, 103402*. doi:10.1016/j.ijnurstu.2019.103402

Robinson, A. L., Broachie, A., & Lafrance, G. A. (2013). “I want help!”: Psychologists’ and physicians’ competence, barriers, and needs in the management of eating disorders in children and adolescents in Canada. *Canadian Psychology, 54*(3), 160-165. doi:10.1037/a0032046

Rockwell, J. M. & Riegel, B. (2001). Predictors of self-care in persons with heart failure. *Heart & Lung, 30*(1), 18- 25. doi:10.1067/mhl.2001.112503

Rosling, A., Ros, H. S., & Swenne, I. (2016). One-year outcome and incidence of anorexia nervosa and restrictive eating disorders among adolescent girls treated as out-patients in a family-based setting. *Upsala Journal of Medical Sciences, 121*(1), 50-59. doi:10.3109/03009734.2016.1141810

Rubin, H. J. & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: SAGE Publishing.

Ryan, V., Malson, H., Clarke, S., Anderson, G., & Kohn. M. (2006). Discursive constructions of ‘eating disorders nursing’: An analysis of nurses’ accounts of nursing eating disorder patients. *European Eating Disorders Review, 14*, 125-135. doi:10.1002/erv.666

Sawicki, G. S., Kelemen, S., & Weitzman, E. R. (2014). Ready, set, stop: Mismatch between self-care beliefs, transition readiness skills, and transition planning among adolescents, young adults, and parents. *Clinical Pediatrics, 53*(11), 1062-1068. doi:10.1177/000992281451169

Schmidt, U., Andiappan, M., Grover, M., Robinson, Perkins, S., Dugmore, O., …Williams, C. (2008). Randomised controlled trial of CD_ROM-based cognitive behavioural self-care for bulimia nervosa. *The British Journal of Psychiatry, 193*, 493-500. doi:10.1192/bjp.bp.107.046607

Schmidt, U., Landau, S., Pombo-Carril, M. G., Bara-Carril, N., Reid, Y., Murray, K., …Katzman, M. (2006). Does personalized feedback improve the outcome of cognitive-behavioural guided self-care in bulimia nervosa? A preliminary randomized controlled trial. *The British Journal of Clinical Psychology, 45*(1), 111-121. doi:10.1348/014466505X29143

Schmidt, U., Lee, S., Beecham, J. Perkins, S., Treasure, J., Yi, L., … Eisler, I. (2007). A randomized controlled trial of family therapy and cognitive behavioural therapy guided self-care for adolescents with bulimia nervosa and related disorders. *The American Journal of Psychiatry, 164*(4), 591-598. doi:10.1176/ajp.2007.164.4.591

Scott, C. M. & Hofmeyer, A. T. (2007). Understanding complexity: Critically analyzing context to understand interdisciplinary research. *Journal of Interprofessional Care, 21*(5), 491-501. doi:10.1080/13561820701605474

Seah, X. Y., Tham, X. C., Kamaruzaman, N. R., & Yobas, P. K. (2017). Knowledge, attitudes and challenges of healthcare professionals managing people with eating disorders: A literature review. *Archives of Psychiatric Nursing, 31*, 125-136. doi:10.1016/j.apnu.2016.09.002

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22,* 63-75. doi:10.3233/EFI-2004022201

Sheridan, G. & McArdle, S. (2016). Exploring patient’s experiences of eating disorder treatment services from a motivational perspective. *Qualitative Health Research, 26*(14), 1988-1997. doi:10.1177/1049732315591982

Skelton, K., Evans, R., LaChenaye, J., Amsbary, J., Wingate, M., & Talbott, L. (2018). Utilization of online focus groups to include mothers: A use-case design, reflection, and recommendations. *Digital Health, 4,* 1-6. doi:10.1177/2055207618777675

Slane, J. D., Klump, K. L., McGue, M., & Iacono, W. G. (2014). Developmental trajectories of disordered eating from early adolescence to young adulthood: A longitudinal study. *International Journal of Eating Disorders, 47*, 793-801. doi:10.1002/eat.22329

Snell, L., Crowe, M., & Jordan, J. (2010). Maintaining a therapeutic connection: Nursing in an inpatient eating disorder unit. *Journal of Clinical Nursing*, *19*, 351-258. doi:10.1111/j.1365-2702.2009.03000.x

Sohn, B. K. (2017). Phenomenology and qualitative data analysis software (QDAS): A careful reconciliation. Qualitative Social Research, 18(1). Retrieved from the PsycINFO database.

Spichiger, E., Wallhagen, M. I., & Benner, P. (2005). Nursing as a caring practice from a phenomenological perspective. *Scandinavian Journal of Caring Science, 19*, 303-309. doi:10.1111/j.1471-6712.2005.00350.x

Standing, M. (2009). A new critical framework for applying hermeneutic phenomenology. *Nurse Researcher*, *16*(4), 20- 30. doi:10.7748/nr2009.07.16.4.20.c7158

Statistics Canada (2016). *Census profile: 2016 census*. Retrieved from https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/details/Page.cfm?Lang=E&Geo1=PR&Code1=35&Geo2=&Code2=&Data=Count&SearchText=Ontario&SearchType=Begins&SearchPR=01&B1=All&GeoLevel=PR&GeoCode=35

Stewart, T. M. & Williamson, D. A. (2004). Multidisciplinary treatment of eating disorders: Primary goals and content of treatment. *Behavior Modification, 28*(6), 831-853. doi:10.1177/0145445503259854

Stewart, S. L., Kam, C., & Baiden, P. (2014). Predicting length of stay and readmission for psychiatric inpatient youth admitted to adult mental health beds in Ontario, Canada. *Child and Adolescent Mental Health*, *19*(2), 115-121. doi:10.111/camh.12022

Stice, E., Marti, N., & Rohde, P. Prevalence, incidence, impairment, and course of the proposed DSW-5 eating disorder diagnoses in an 8-year prospective community study of young women. *Journal of Abnormal Psychology, 122*(2), 445-457. doi:10.1037/aa0030679

Stuhldreher, N., Konnopka, A., Wild, B., Herzog, W., Zipfel, S., Lowe, B., & Konig, H. (2012). Cost-of-illness studies and cost-effectiveness analyses in eating disorders: A systematic review. *International Journal of Eating Disorders*, *45*, 476-491. doi:10.1002/eat.20977

Sungot-Borgen, J. & Torstveit, M. K. (2004). Prevalence of eating disorders in elite athletes is higher than the general population Clinical Journal of Sport Medicine, 14(1), 25-32. doi:10.1097/00042752-200401000-00005

Thompson-Benner, H., Satir, D. A., Franko, D. L., & Herzog, D. B. (2012). Clinical reactions to patients with eating disorders: A review of the literature. Psychiatric Services, 63(1), 73-78. doi:10.1176/appi.ps.201100050

Thompson, C. & Park, S. (2016). Barriers to access and utilization of eating disorder treatment among women. *Archives of Women's Mental Health, 19*, 753-760. doi:10.1007/s00737-016-0618-4

Thorne, S. (1995). On-campus physicians witnessing changes in medical problems faced by university students. *Canadian Medical Association Journal, 154*(1), 77- 79. Retrieved from the MEDLINE Plus database.

Tierney, S. (2008). The individual within a condition: A qualitative study on young people's reflections on being treated for anorexia nervosa. *Journal of the American Psychiatric Nurses Association*, *13*(6), 368-375. doi:10.1177/1078390307309215

Tomba, E., Offidani, E., Tecuta, L., Schumann, R., & Ballardini, D. (2014). Psychological well-being in out-patients with eating disorders: A controlled study. *International Journal of Eating Disorders*, *47*, 252-258. doi:10.1002/eat.22197

Toulany, A., Wong, M., Katzman, D. K., Akseer, N., Steinegger, C., Hancock-Howard, R. L., & Coyte, P. C. (2015). Cost analysis of inpatient treatment of anorexia nervosa in adolescents: Hospital and caregiver perspectives. *CMJA Open, 3*(2), 192-197. doi:10.9778/cmjao.20140086

Treasure, J. & Schmidt, U. (2002). Ready, willing and able to change. *European Eating Disorders Review*, *9*, 4-18. doi:10.1002/erv.390

Tuffour, I. (2017). A critical overview of interpretative phenomenological analysis: A contemporary qualitative research approach. *Journal of Healthcare Communications, 2*(4), 52-56. doi:10.4172/2472-1654.100093

Tuohy, D., Cooney, A., Dowling, M., Murphy, K., & Sexsmith, J. (2013). An overview of interpretative phenomenology as a research methodology. *Nurse Researcher, 20*(6), 17-20. doi:10.7748/nr2013.07.20.6.17.e315

Van Ommen, J., Meerwijk, E. L., Kars, M., Van Elburg, A., & Van Meijel, B. (2009). Effective nursing care of adolescents diagnosed with anorexia nervosa: The patients' perspective. *Journal of Clinical Nursing, 18*, 2801-2808. doi:10.1111/j.1365-2702.2009.02821.x

Vo, M., Lau, J., & Rubinstein, M. (2016). Eating disorders in adolescent and young adult males: Presenting characteristics. *Journal of Adolescent Health, 59*(4), 397-400. doi:10.1016/j.adohealth.2016.04.005

Von Ranson, K. M., Wallace, L. M., & Stevenson, A. (2013). Psychotherapies provided for eating disorders by community clinicians: Infrequent use of evidence-based treatment. *Psychotherapy Research, 23*(2), 333-343. doi:10.1080/10503307.2012.735377

Walden University (n.d.). *Research Ethics FAQs for doctoral students in the clinical/interventional fields*: Practical tips for avoiding delays and problems in the research approval process. Retrieved from https://academicguides.waldenu.edu/researchcenter/orec/documents

Waller, G. (2012). The myths of motivation: Time for a fresh look at some received wisdom in the eating disorders? *International Journal of Eating Disorders, 45*, 1-16. doi:10.1002/eat.20900

Wallier, J., Vibert, S., Berthoz, S., Huas, C., Hubert, T., & Godard, N. (2009). Dropout from inpatient treatment for anorexia nervosa: Critical review of the literature. *International Journal of Eating Disorders, 42*, 636-647. doi:10.1002/eat.20609.

Walsh, R. A. (1994). The approach of the human science researcher: Implications for the practice of qualitative research. *The Humanistic Psychologist, 23*(3), 333-344. doi:10.1080/08873267.1995.9986834

Warren, C. S., Schafer, K. J., Crowley, M. J., & Olivardia, R. (2013). Demographic and work-related correlates of job burnout in professional eating disorder treatment providers. *Psychotherapy, 50*(4), 553-564. doi:10.1037/a0028783

Weissman, R. S. & Roselli, F. (2017). Reducing the burden of suffering from eating disorders: Unmet treatment needs, sots of illness, and the quest for cost-effectiveness. *Behavior Research and Therapy, 88*, 49-64. doi:10.1016/j.brat.2016.09.006

Weltzen, T., Kay, B., Cornella-Carlson, T., Timmel, P., Klosterman, E., Kinnear, K. A;.,… & Bean, P. (2014). Long-term effects of a multidisciplinary residential treatment model on improvement of symptoms and weight in adolescents with eating disorders. *Journal of Groups in Addiction & Recovery, 9*, 71-85. doi:10.1080/1556035X.2014.868765

Williams, S., & Reid, M. (2012). ‘It’s like there are two people in my head’: A phenomenological exploration of anorexia nervosa and its relationship to the self. *Psychology and Health, 27*(7), 798-815. doi:10.1080.08870446.2011.595488

Winston, A. P., Paul, M. & Juanola-Borrat, Y. (2012). The same but different? Treatment of anorexia nervosa in adolescents and adults. *European Eating Disorders Review, 20*, 89-93. doi:10.1002/erv.1137

Wiseman, C. V., Sunday, S. R., Klapper, F., Harris, W. A., & Halmi, K. A. (2001). Changing patterns of hospitalization in eating disorder patients. *International Journal of Eating Disorders*, *30*(1), 69-74. doi:10.1002/eat/1055

Woodyatt, C. R., Finneran, C. A., & Stephenson, R. (2016). In-person versus online focus group discussions: A comparative analysis of data quality. *Qualitative Health Research, 26*(6), 741-749. doi:10.1177/1049732316631510

Wright, K. M. (2015). Maternalism: A healthy alliance for recovery and transition in eating disorder services. *Journal of Psychiatric and Mental Health Nursing, 22,* 431-439. doi:10.111/jpm.12198

Zaider, T. I., Johnson, J. G., & Cockell, S. J. (2000). Psychiatric co-morbidity associated with eating disorder symptomatology among adolescents in the community. *The International Journal of Eating Disorders*, *28*(1), 58-67. doi:10.1002/(SICI)1098-108X(200007)28:1<58::AID-EAT7>3.0.CO;2-V

Zugai, J., Stein-Parbury, J., & Roche, M. (2013). Effective nursing care of adolescents with anorexia nervosa: A consumer perspective. *Journal of Clinical Nursing, 22,* 2020-2029. doi:10.111/jocn.112182

Zwaanswijk, M. & van Dulman, S. (2014). Advantages of asynchronous online focus groups and face-to-face focus groups as perceived by child, adolescent, and adult participants: A survey study. *Research Notes*, *7*, 756. doi:10.1186/1756-0500-7-756

Appendix A: Letter to Eating Disorder Healthcare Professionals

<Insert Date>

Dear OCOPED Colleague,

I am seeking the help of patients recruited through fliers posted at your agency in a research endeavor being conducted as part of my doctoral degree. I am currently conducting a research study examining the experiences of young adults receiving outpatient eating disorder care in Ontario. Despite strong research demonstrating efficacy of community-based eating disorder care and so much of the funding and care delivery in Ontario being focused on outpatient treatment, we know very little about the experience of receiving such care. As a nurse practitioner in this field I also know this to be true anecdotally. Further, there is a paucity of evidence to support the role of nurses in community-based eating disorder care, so I aim to explore patient perceptions of the nursing care they receive.

Your agency has been identified as having an out-patient eating disorder treatment program delivered in part or in full by nurses and/or nurse practitioners and I am writing to request your assistance in advertising a recruitment flyer for my study. I am hoping to recruit males and females, aged 18-22 with Anorexia Nervosa or Bulimia Nervosa, to participate in asynchronous online focus groups to discuss their experiences of eating disorder treatment.

If you agree to participate, I would ask you to kindly post the attached fliers in areas of your facility with high visibility to patients. I have taken the liberty of attaching the recruitment flyer. If your organization requires a formal letter of cooperation, I am happy to collaborate with the appropriate authority to complete your organization’s forms.

I invite you to contact me anytime should you have any questions or concerns. Your consideration in this matter is most appreciated

Respectfully,

Hali Sitarz, NP, MN, PhD(c)
Walden University, PhD in Nursing Program

Appendix B: Recruitment Flyer

What is this study about?
The goal is to understand the experiences of young people in community-based eating disorder treatment

Who can participate?
Men and women aged 18-22 who have Anorexia Nervosa or Bulimia Nervosa
Those who can read and write fluently in English
Those who have reliable Internet access and who would be comfortable answering questions online

What is involved?
Participants will complete a brief survey and then discuss questions about eating disorder care in a private online group forum. Although measures will be taken to protect participant identity, no online discussion can ever be 100% private.
The forum will be open 24/7 for a two week period. Participants will be asked to answer 11 questions with their own opinions and respond to the answers of their peers as they see fit. The time commitment will vary based on how much you participate.

What are the benefits of participating?
You will contribute the most valuable and important information about community-based eating disorder care-- the patient experience!
This knowledge may influence further research, policy change, program funding and patient-focused eating disorder care.

How do I ask questions or get involved?
Contact Hali Sitarz, doctoral student/researcher for questions at hali.sitarz@waldenu.edu

Find out more and/or take the survey at **https://www.surveymonkey.com/r/XT26W8Q**

Participate in Research!

“Understanding the Experiences of Young Adults Receiving Eating Disorder Care in the Community”

Appendix C: Sample Letter of Potential Participant Cooperation

<Date>

Dear Potential Participant,

Thank you so much for your interest in my study, “Understanding the Experiences of Young Adults Receiving Eating Disorder Care in the Community.” As a nurse practitioner working with adolescents and young adults with eating disorders for many years, I have developed an appreciation for the challenges that these diseases present to those who have them, but also, I have witnessed amazing strength and resiliency in patients during their treatment. Unfortunately, little research has been done to examine what life is really life for young people during community-based treatment. Health care professionals can benefit from hearing this from the people who matter most in treatment- the patients. I hope you too will benefit from sharing your experiences and contributing to efforts to improve eating disorder care in Ontario.

Here is some information that you need to know about the study.

- Your participation is voluntary, and you can change your mind at any time.
- Since this study is examining treatment across Ontario and is based on the opinions of both men and women, participants may be selected on the basis of their gender, location and/or treatment history. You will be asked to complete a brief survey of basic demographic data (i.e. age, gender, city, eating disorder diagnosis, length of treatment, etc.) and once the researcher ensures that you’ve met all the criteria, you will be contacted to begin participating.
- Being in this study involves discussion of eating disorders and treatment, which can sometimes be sensitive subjects. The risk of discussing these subjects may involve experiencing minor discomforts of stress or becoming upset, similar to the risks you encounter during everyday life.
- You will be asked to log into an online forum and answer several questions about your experiences in eating disorder treatment. Other participants will be able to see your comments so to protect your identity, you are strongly encouraged to use a pseudonym (a fake name). The online forum will be password protected so it is unlikely that anyone other than the researcher and other participants will see what you write, however, there is no way to 100% safeguard privacy on the Internet so it is important you remember this and be very cautious about what you choose to share as a result. Several security measures will be taken to protect your privacy, but unfortunately, there is no way to 100% guarantee that people outside of the study won’t be able to access your responses.
- Access to the discussion forum will be open 24/7 for a period of two weeks and during this time you can participate as much or as little as you’d like. Ideally,

you can post your initial answers to the questions and then log in again later to see if you'd like to contribute any more to responses of others in the discussion.

- Following completion of the study, your name will be removed from any contributions you make to the discussion. These contributions may be shared with my teachers or may be used in journal publications in the future.
- The potential benefits of this study may include a better understanding of patients' experiences in community-based eating disorder treatment which could be used for education, funding, policy creation, and program development purposes.

If you have any questions or concerns, please contact me anytime.

You are the expert of your own experience and I sincerely look forward to learning from you.

Sincerely,

Hali Sitarz
Principle Researcher

Appendix D: Focus Group Discussion and Research Question Alignment

1. Please tell me about your present experience as a patient receiving eating disorder care in the community.
   1b. How has your experience been different in the past?
2. How does community-based eating disorder care impact your life?

3. How is the care you receive in the community different than that that you have received as an in-patient?
   3b. How is the culture different between in-patient and community-based care?
4. Please describe the role you play in your care.

5. What does your eating disorder mean to you?
   5b. Has this meaning changed?
6. Please describe your experiences in the health care system since the onset of your eating disorder

7. Do you feel that the place you live impacts your healthcare?

8. Please describe your experiences with health care professionals who have been involved in your care.

9. Have your experiences with nurses differed from your experiences with other health care professionals? If yes, please explain.

10. What do you think the ideal role is for nurses to play in community-based eating disorder care?

11. How have your experiences with community-based eating disorder care shaped you?

Appendix E: Survey Monkey Screener for Inclusion Criteria

1. Consent

2. Are you between the ages of 18-22, with a diagnosis of Anorexia Nervosa or Bulimia Nervosa, and currently receiving community-based (outpatient) eating disorder treatment in Ontario?

☐ Yes. ☐ No

3. Please indicate your age and eating disorder diagnosis

☐ 18 ☐19 ☐ 20 ☐ 21 ☐ 22 ☐ Anorexia Nervosa ☐ Bulimia Nervosa

4. Please indicate your gender/sex

☐ Female. ☐ Male. ☐ Other gender/sex

5. What city/town do you live in? _______________

6. How many <u>times</u> have you been treated as an <u>in-patient</u> (hospital or residential treatment away from home) for your eating disorder?

0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 or more ☐

7. How many <u>years</u> have you been treated as an <u>out-patient</u> (while you continue to live at home) for your eating disorder?

0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 or more☐

8. On a scale of 0-10, how comfortable are you discussing your eating disorder and treatment history in an online environment?

0 (not at all comfortable) 5 (somewhat comfortable) 10 (very comfortable)

9. On which dates are you available to participate in this study between XXX date and XXX date?

Day 1 (X date) ☐ X2 date ☐ X3 date ☐ X4 date☐ X5 date☐ X6 date☐
X7 date☐ X9 date) ☐ X9 date ☐ X10 date ☐ X11 date☐ X12 date☐
X13 date☐ X14 date☐ I am not available to participate during any of these dates ☐

10. What is your email address? _______________**_please remember that if your email address contains all or part of your name, this may compromise your anonymity_**